

# Handbook for HIV Prevention Community Planning

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3. The third part of the report is a description of the research methodology. It discusses the methods used to collect and analyze the data.

4. The fourth part of the report is a presentation of the results of the study. It discusses the findings of the research and compares them with the results of other studies.

5. The fifth part of the report is a discussion of the implications of the study. It discusses the significance of the findings and their potential applications.

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7. The seventh part of the report is a list of references. It lists the sources of information used in the study.

8. The eighth part of the report is an appendix. It contains additional information that is not included in the main body of the report.

9. The ninth part of the report is a glossary. It defines the terms used in the report.

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12. The twelfth part of the report is a list of symbols. It provides a summary of the symbols used in the report.



## Acknowledgments

The material in this handbook is a compilation and synthesis of the work of many researchers and practitioners in the wide array of disciplines that comprise participatory community planning. Each chapter includes a list of references and resources used; the final chapter offers a summary of resources useful to HIV prevention community planners.

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## Preface

The widespread adoption of participatory community planning marks an important change in the way HIV prevention programs are being developed in states and localities across the country. Beginning in January 1994, state, local, and U.S. territorial health departments that receive HIV prevention funding from the Centers for Disease Control and Prevention (CDC) have been asked to seek significant and meaningful involvement of their communities in developing comprehensive HIV prevention plans. These community plans will form the basis for applications for future cooperative agreement funding under Program Announcement #300.

CDC has advocated community input in past HIV prevention funding cycles, and many project areas have involved community participants in various aspects of program planning and delivery. Previous CDC funding guidelines also specified the kinds of interventions to be undertaken and the relative allocation of resources to each program activity. The current initiative provides specific guidance and support to project areas to help develop a more participatory process in the identification of appropriate program priorities for the area.

HIV prevention community planning, as defined by CDC's *Supplemental Guidance on HIV Prevention Community Planning for Noncompeting Continuation of Cooperative Agreements for HIV Prevention Projects*, is an ongoing process by which public health agencies (grantees) share responsibility with other state/local agencies, nongovernment organizations, and community representatives for identifying needs, determining priorities, and developing comprehensive HIV prevention plans. Participatory community planning recognizes that, although grantees are responsible for and

accountable for the public health in their jurisdictions, they may be limited in their scope and ability to solve complex health, social, economic and environmental problems alone. HIV prevention programs developed without community participation and a sound scientific basis are unlikely to be successful in preventing the spread of HIV infection or to garner the necessary public support.

Although the CDC *Supplemental Guidance* seeks to assure a degree of consistency in planning processes in all project areas, its language is intentionally crafted to permit flexibility in addressing grantee needs and circumstances. Specific information is provided in the guidance on the principles of participatory planning, selection considerations for participants, roles and responsibilities of all parties, and factors to be used in setting program priorities. However, grantees are expected to collaborate with other community partners in determining the best way to implement participatory planning in their own project areas.

This handbook represents a first step in developing a technical assistance support system for project areas undertaking participatory community planning for HIV prevention. It provides a distillation of useful principles and approaches in key areas as well as identification of additional resources that project areas may find helpful. It is offered with the clear understanding that communities will vary in their experience and approach to creating an effective and workable process and that no document can fully address the range of issues to be encountered. Additional support will be provided by CDC through a network of technical assistance resource organizations that can provide consultation in key aspects of HIV prevention community planning.

The first part of the report deals with the general situation of the country. It is a very interesting and informative study of the country's development. The author has done a great deal of research and has gathered a wealth of material. The report is well written and is a valuable contribution to the study of the country's development. It is a must-read for anyone interested in the country's development.

The second part of the report deals with the country's economic situation. It is a very detailed and comprehensive study of the country's economy. The author has done a great deal of research and has gathered a wealth of material. The report is well written and is a valuable contribution to the study of the country's economy. It is a must-read for anyone interested in the country's economy.

The third part of the report deals with the country's social situation. It is a very detailed and comprehensive study of the country's society. The author has done a great deal of research and has gathered a wealth of material. The report is well written and is a valuable contribution to the study of the country's society. It is a must-read for anyone interested in the country's society.

The fourth part of the report deals with the country's political situation. It is a very detailed and comprehensive study of the country's politics. The author has done a great deal of research and has gathered a wealth of material. The report is well written and is a valuable contribution to the study of the country's politics. It is a must-read for anyone interested in the country's politics.

The fifth part of the report deals with the country's cultural situation. It is a very detailed and comprehensive study of the country's culture. The author has done a great deal of research and has gathered a wealth of material. The report is well written and is a valuable contribution to the study of the country's culture. It is a must-read for anyone interested in the country's culture.

The sixth part of the report deals with the country's environmental situation. It is a very detailed and comprehensive study of the country's environment. The author has done a great deal of research and has gathered a wealth of material. The report is well written and is a valuable contribution to the study of the country's environment. It is a must-read for anyone interested in the country's environment.

The seventh part of the report deals with the country's international situation. It is a very detailed and comprehensive study of the country's international relations. The author has done a great deal of research and has gathered a wealth of material. The report is well written and is a valuable contribution to the study of the country's international relations. It is a must-read for anyone interested in the country's international relations.

The eighth part of the report deals with the country's future. It is a very detailed and comprehensive study of the country's future. The author has done a great deal of research and has gathered a wealth of material. The report is well written and is a valuable contribution to the study of the country's future. It is a must-read for anyone interested in the country's future.

The ninth part of the report deals with the country's conclusion. It is a very detailed and comprehensive study of the country's conclusion. The author has done a great deal of research and has gathered a wealth of material. The report is well written and is a valuable contribution to the study of the country's conclusion. It is a must-read for anyone interested in the country's conclusion.

The tenth part of the report deals with the country's appendix. It is a very detailed and comprehensive study of the country's appendix. The author has done a great deal of research and has gathered a wealth of material. The report is well written and is a valuable contribution to the study of the country's appendix. It is a must-read for anyone interested in the country's appendix.

## Introduction



# Introduction

This handbook is one initial element of a broad-based technical assistance effort designed to help state, local, and territorial health departments implement the *Supplemental Guidance on HIV Prevention Community Planning for Noncompeting Continuation of Cooperative Agreements for HIV Prevention Projects* issued by the Centers for Disease Control and Prevention (CDC). The handbook is intended to assist CDC HIV Prevention Cooperative Agreement grantees in establishing and maintaining HIV prevention community planning groups. It also covers several of the key tasks that will need to be addressed by the planning groups as they develop comprehensive HIV prevention program plans.

The handbook has been developed in response to expressed needs by grantees as they have begun to implement the HIV prevention community planning process, and it reflects CDC's desire to provide ongoing and responsive technical assistance throughout the process. As participants gain experience with HIV prevention community planning, revisions or future editions of the handbook may be needed.

## HOW THIS HANDBOOK IS ORGANIZED

**H**andbook for HIV Prevention Community Planning is composed of eight chapters that correspond to the essential principles of a community planning process outlined in the *Supplemental Guidance*. Chapters 1 through 3 cover issues relating to forming and maintaining community planning groups, specifically establishing and managing the process in an open, inclusive, and participatory

way and resolving disputes and conflict of interest issues. Chapters 4–8 address the specific tasks before planning groups. Chapter 4 provides an overview of major categories of HIV/AIDS-related data as well as an inventory of specific data sources, which planning groups should review in developing an epidemiologic profile of their community. Chapter 5 discusses in detail the steps involved in conducting a needs assessment and it details various types of needs assessment data collection methods. Chapters 6 and 7 address the selection of HIV prevention program interventions, first by describing a process for priority-setting and decision-making, and second by discussing three major attributes of possible interventions that planning groups need to consider when setting intervention priorities. Chapter 8 discusses evaluating the community planning process. The final chapter of the handbook, Chapter 9, presents a summary of resources for HIV prevention community planning. The chapter also includes a copy of the *Supplemental Guidance*.

Several of the chapters contain a section entitled "Notes from the Field." These sections represent a synthesis of major findings from a series of interviews conducted with AIDS directors and other project area staff regarding their experiences with community plan-

The Community Planning Process	Community Planning Tasks	Additional Resources
1. Ensuring Community Participation	4. Developing an Epidemiologic Profile	9. Resources for HIV Prevention Community Planning
2. Valuing and Managing the Community Planning Process	5. Assessing and Setting Priorities for Community Needs	
3. Conflict of Interest and Dispute Resolution	6. Setting Prevention Program Priorities	
	7. Selecting Among HIV Prevention Interventions: Theoretical Basis, Effectiveness, and Cost-Effectiveness	
	8. Evaluating the Community Planning Process	

ning. AIDS directors were asked to describe past or current HIV-related planning experiences in which the health department solicited community participation and input. From their comments, a rich array of lessons learned, strategies, and insights "from the field" have been distilled that have implications for and applications to the HIV prevention community planning process. A number of noteworthy quotations from these interviews are shown throughout the handbook. Also shown are comments by representatives of national minority and other nongovernmental organizations, drawn from a meeting for HIV prevention community planning technical assistance providers, held in Atlanta GA, April 7-8, 1994.

## HOW TO USE THIS HANDBOOK

This handbook has been designed to assist grantees in establishing and maintaining community planning groups and to assist those groups in their HIV prevention planning tasks. It is comprised of a collection of chapters, each addressing a key component of community planning. Together, these chapters provide a broad overview of issues and approaches in implementing the process as a whole. Individually they have been developed to provide as much practical support as possible at this early stage of development of the process. Several chapters include handouts that can be used by project area staff and planning groups for orientation and training, for presentations, or as tools in undertaking specific tasks. Other chapters propose models and criteria that may be considered by individual project areas in developing approaches tailored to their own needs. The handbook is not intended as a quick primer on community planning. The chapters have been developed to provide initial substantive support to each step of the process, and may be useful in different ways at different stages.

The handbook may also be a useful tool for other types of group or coalition activities undertaken by

health departments. The references, individuals, and organizations cited throughout the document should be a helpful resource for a wide range of planning activities.

## ONE FINAL NOTE TO USERS OF THIS HANDBOOK

*Handbook for HIV Prevention Community Planning* is but one component of an ongoing technical assistance effort designed to assist state, local, and territorial health departments in implementing HIV prevention community planning. It is recognized that while written materials, such as this handbook, are essential, many of the community planning issues and challenges faced by health departments will be unique. Often, one-on-one problem-solving efforts will be needed to thoroughly address the situation.

For this reason, a network of interactive technical assistance has been developed, allowing the recipient to ask questions, discuss issues, and develop solutions with experts in a particular subject area. Organized by major content area, the interactive technical assistance includes on-site and telephone consultations by multiple external providers of service. Of note, consultation with national minority organizations regarding issues of parity, inclusion, and representation in the planning process is available, as is consultation on behavioral science issues through the Academy for Educational Development.

For health department grantees, the access point to this resource base is their Project Officer in the Division of STD/HIV Prevention, National Center for Prevention Services (NCPS), CDC. The list of NCPS Project Officers is included in Chapter 9. Project Officers will work with grantees to ensure appropriate diagnosis of the issue at hand, and will link the grantee to the best source of external technical assistance available in the network.



# Chapter 1

## Ensuring Community Participation

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# Chapter 1

## Ensuring Community Participation

### 1.1 OVERVIEW

Participatory planning for HIV prevention is designed to secure a broad range of perspectives, build consensus, and mobilize resources to make decisions about HIV prevention programs. Its premise is that HIV prevention programming must consider the special needs of affected populations and, in order to do so effectively, should use the resources of communities as well as the expertise of various disciplines and perspectives in the community.

Securing a range of input requires the full involvement of the community. This can be achieved through a participatory planning process, whose foundation is a planning group that reflects the diversity of the community. Efforts to organize a diverse planning group should be guided by the principles of inclusiveness, representation, and parity.

This chapter first discusses the benefits and obstacles to participatory planning. An explanation of the principles of inclusiveness, representation, and parity then follows. The remainder of the chapter covers practical steps to organizing and starting a planning group. These steps include: determining whether to adapt an existing group or create a new structure; identifying members of the planning group (ensuring that inclusiveness and representation are present); and training group members to ensure parity so that all can participate fully and equally. At the end of the chapter there is a section entitled, "Notes from the Field: Ensuring Community Participation." These "Notes" are a synthesis of major findings from interviews conducted with state AIDS directors and other project area staff regarding their experience with establishing participatory community planning groups.

These early organizing steps are critical to the ongoing functioning of the planning group. Chapter 2, *Valuing and Managing the Community Planning Process*, outlines suggested processes to ensure the ongoing efficient operation of the planning effort.

### 1.2 DEFINITION OF PARTICIPATORY PLANNING

Participatory planning is the process of identifying needs and making decisions through the broad-based involvement of a wide range of viewpoints, wherein differences in background, perspective, and experience are essential and valued. It

#### Definitions

*Participatory Planning*—An ongoing process in which state/local health departments share responsibility for developing a (comprehensive HIV prevention) plan with other governmental and non-governmental agencies, and representatives of communities and groups at risk for HIV infection or already infected (AED, 1994). Key characteristics include a membership that is representative of all stakeholders; an attitude that values and uses differences; and shared learning, input, responsibility, and decision-making.

*Inclusiveness*—Assurance that all affected communities are represented and involved in a meaningful manner in the community planning process.

*Representation*—Assurance that those who are representing a specific community truly reflect that community's values, norms, and behaviors.

*Parity*—The condition whereby all members of the HIV prevention community planning group have equal opportunity for input and participation as well as equal voice in voting and other decision-making activities.

*Empowerment*—A process by which a person facilitates opportunities for his or her own capacity-building and skill-building, resulting in greater self-determination.

represents an opportunity to stimulate and coalesce community energies, interests, and resources in a collective response. (*Community Health Change*, unpublished)

Participatory planning for HIV prevention requires both balance and integration of perspectives and input (*Community Health Change*, unpublished), such as epidemiologic information, programmatic experience, and the perspectives of affected communities and persons. Equal importance is placed on the voices of public health authorities, affected communities, service providers, and expert and specialized disciplines. Because it has a broadened focus, participatory planning should complement rather than replace the existing public health planning efforts.

Participatory planning also requires a community environment that is receptive to a group planning process. A given level of trust and collaboration must exist among agencies.

Similarly, an efficient and widely understood process must be established for operating the planning body, along with ongoing communication among members to ensure that the knowledge base of all participants is broadened. Also, the mission of the group must be reasonable and doable within the resources that are available to make the effort happen.

The mechanism advanced by CDC to garner community input in HIV prevention planning is a participatory planning process. CDC outlines reasons for including communities affected by the HIV epidemic in HIV prevention planning. First, more expertise will be available in designing prevention programs that consider the special characteristics, needs, and preferences of groups they are designed to reach. Second, design of comprehensive HIV prevention programs requires the multifaceted input of various communities affected by HIV, including those currently experiencing disproportionate rates of infection as well as those at disproportionate risk.

Finally, change is more likely to be successful if people are involved in its initiation and promotion. Local values, norms, and behavior patterns have a significant impact on individual attitudes and behaviors. Because behavior change is best brought about by altering community norms about health behavior, large scale behavior change requires that the people heavily affected by a problem be involved in defining the problem, participate in planning and instituting steps to resolve the problem, and be responsible for the operation of programs. (*Community Health Change*, unpublished)

### 1.2.1 Key Principles of Participatory Planning: Inclusiveness, Representation, Parity

Participatory planning implies faith that a planning group and the participatory process offer the best means for making decisions about HIV prevention programming. The integrity of the effort will be influenced in part by the planning group's ability to contribute a diverse and well-informed body of knowledge to the planning effort. It is therefore important to identify standards to measure the adequacy and capacity of the group to carry out its mandate. Principles identified by CDC to guide formation of the planning group include inclusiveness, representation, and parity.

- **Inclusiveness** — Assurance that all affected communities are represented in the community planning process.

Key questions: Are all parties involved? Has adequate outreach been conducted in identifying critical perspectives to include?

- **Representation** — Assurance that those who are representing a specific community truly reflect that community's values, norms, and behaviors.

Key questions: Do members understand and adequately represent the communities and perspectives for which they were chosen? For example, are representatives well-respected in their own communities and informed about their needs? Are members competent in their given field of expertise?

In assessing how truly an individual represents a constituency, consideration should be given to whether or not the individual is acting in the interests of the constituency. The member should be driven by the formal and informal judgment and consent of the constituency. This does not mean that the individual solely: 1) serves as a messenger by just conveying constituent wishes and acting on their requests, or 2) acts as a guardian by doing what he/she considers to be in their best interests, without consulting them (Marmor and Morone, 1980).

- **Parity**—The condition whereby all members of the planning group have equal opportunity and capacity to provide input and to participate, as well as an equal voice in voting and other decision-making activities.

Key questions: Are all members adequately prepared to be full participants? Is each member well-versed and comfortable with the group decision-making pro-

cess? Are all members able to attend meetings on a regular basis? Do all parties understand HIV/AIDS prevention, the role of public health, and unique community perspectives on HIV prevention?

Each of these standards needs to be considered at every stage of the planning group formation process, including identification, nomination, selection, and training of planning group members. Inclusiveness and representation require specific attention when identifying, nominating, and selecting planning group members. Parity is a guiding principle in determining the training and resource needs of group members.

### 1.2.2 Recognizing Differences

In order for a diverse group to work well among itself and with the community, it needs to recognize, respect, and value differences among group members. Each planning group member, whether acting as an agency representative or as an individual, brings to the group his or her unique identification with race/ethnicity, gender, age, sexual orientation, and a host of other characteristics. Members also bring the perspectives and philosophies of their organizations and disciplines. Health department officials express the values of public health. Community agencies feel strongly about their preeminence in carrying out effective street-based prevention efforts. The challenge to the group is first, to understand these differences and second, to integrate them into the group.

For HIV prevention community planning groups, this kind of diversity is required if a group is to be truly representative of and responsive to its project area. Yet, diversity can raise challenges for a group in three key areas:

- **Process.** Different groups think about and act upon projects and tasks differently. There may be marked differences in decision-making styles, timeframes, and methods for planning and acting.
- **Language.** Different cultural groups communicate with each other in certain ways, using particular words and figures of speech to express themselves.
- **Etiquette.** Different groups have certain norms for acceptable and unacceptable behavior. These norms and taboos are particularly important when conflicts arise.

### 1.2.3 Benefits of Participatory Planning

As shown in Table 1-1, HIV prevention programs can realize many positive outcomes through a partici-

patory planning process that is guided by the principles of inclusion, representation, and parity. By building a planning group that is inclusive, a broad spectrum of input and pooling of resources can be realized. Attention to achieving representation can result in true grassroots involvement of affected communities. Attention to parity among members will

#### **Table 1-1: Participatory Planning: How Do HIV Prevention Programs Benefit?**

Participatory planning is built upon a broad range of input and community knowledge. As a result, it can improve HIV prevention programming by providing:

- A more complete picture of community HIV prevention needs.
- Enhanced access to hard-to-reach populations.
- Better targeting of programs to specific populations.
- More comprehensive program planning.
- Enhanced coordination between planning efforts and subsequent HIV prevention delivery.
- Less duplication and fewer gaps in services.
- A broad-based understanding of and support for HIV prevention needs.
- Greater community ownership of and commitment to prevention programs.
- Increased appreciation by the community.
- Increased credibility with affected communities.
- Increased community understanding of and support for health department efforts.
- Investment of resources by other community partners.
- Increased utilization of services.
- An increased voice for the community in program planning and development.
- Improved capacity of participants to assess needs and plan programs.
- An opportunity to develop programs that are more complementary to community desires.
- Involvement of many different community sectors.

result in all members having the capacity to participate fully, thus providing a balanced and accurate reflection of community HIV prevention needs.

- Pooling of resources occurs. This increases power beyond what is possible independently. Ideally, it can amplify resources. Involving community groups, volunteer organizations, advocacy groups, educators, representatives of affected populations, and the leadership of health professions can help bring more voices and skills to the table and help garner public support.
- Duplication of effort is minimized. Bringing together the interests and expertise of groups and individuals can improve the effectiveness and impact of HIV prevention efforts. (Public Health Foundation and the Association of State and Territorial Health Officials, 1987)
- A broad spectrum of input is provided to state and local health departments. This may result in better access to underrepresented populations, better targeting of HIV prevention methods, and enhanced credibility of state and local health department prevention programs.
- Grassroots involvement represents an opportunity to pre-test the acceptability of new programs or ideas; gain wide citizen support; mobilize the efforts of volunteers; incorporate local values, attitudes, and symbols into implementation plans; provide greater access to local leaders, resources, and technical skills not otherwise available; build the layperson's point of view into program delivery; develop local skills and competencies for future community development/opportunities; and enhance local ownership and improved chances of the long-term maintenance of prevention programs. (*Community Health Change*, unpublished)
- Coordination can be brought about between loosely structured agencies and organizations, both public and private.
- A forum can be provided wherein ideas and concerns can be shared and conflicts between organizations and groups can be discussed and resolved.
- Community development and empowerment can occur, whereby important perspectives that otherwise may go unheard are brought into the decision-making forum. These individuals may not currently possess the capacity (i.e., skills and access) to participate fully in the planning process. The planning effort, in order to benefit fully from their involvement, should undertake efforts such as training in group

decision-making and should make provisions to allow for practical participation, such as providing travel funds to allow participants to attend meetings.

#### 1.2.4 Barriers to Participatory Planning

As a rule, there are inherent complications attending efforts to broaden involvement in planning. Multiple differences exist among process participants, including perspectives on the most pressing needs and best programmatic responses; understanding of and preferences for processes to use; and skills and backgrounds of the participants. Barriers to HIV prevention planning require special initiatives to ensure the full participation of all underrepresented groups. More specifically:

- Some members face extreme limitations of time and/or resources that hamper their ability to participate regularly. They may work in agencies that are severely understaffed. Such entities rarely have funds available for travel to meetings.
- Some members may lack the skills needed to participate fully. Skill deficits may be in the areas of: understanding and making effective use of process, group decision-making, and dispute management; comprehending the governmental public health structure; understanding community-based HIV prevention approaches; and analyzing and interpreting epidemiologic and other data.
- Intra-member problems may arise because of diversity differences, communication differences, resistance to change by certain members, previous conflicts, and poor information flow among members.
- Disagreements may arise over membership criteria for the planning group. This may cause a delay in planning or outright resistance to the group's proceeding before these concerns are resolved.
- Some groups and/or individuals may perceive the planning group to be a threat to their sense of autonomy and specific HIV prevention activities.

#### 1.3 ORGANIZING A PLANNING BODY

**K**ey steps in organizing the planning body include the following: determining whether to adapt an existing body or create a new structure; selecting members and insuring that inclusiveness and representation exist; and training members to bring about parity among group members. Addi-

tional activities—such as selecting and preparing co-chairs; creating group structures (e.g., committees, officers, key tasks); and outlining the role of professional staff—are discussed in Chapter 2, *Valuing and Managing the Community Planning Process*.

Standard procedures should be established and followed for all of these steps. Developing this process, up front, will facilitate the organizational task and will minimize questions and criticisms about steps

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*“Prior participation in local planning efforts has left some community members skeptical. It is important that we build ownership of the process.”*

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followed in organizing the group. These organizational procedures should be undertaken when creating a new planning group as well as when adapting an existing planning body.

In forming a planning group, initial organizing efforts may be more efficiently carried out with a limited number of participants. Keeping the early organizing group small may also be the preferred approach for nonparticipants. Some groups will want to wait and see if the planning group is valid before joining (i.e., is it worth their time and effort, does the cost of participating outweigh benefits or vice versa, is there basic disagreement with direction or leadership of the effort?) (CDC, 1993).

The initial organizing group should be diverse and broadly representative to help ensure, to the maximum extent possible, that broad-based participation is obtained at the very beginning so that the credibility of the planning effort is maintained. Throughout, the standards of inclusiveness, representation, and parity need to be followed.

### 1.3.1 Modify a Planning Group or Create a New One

Grantees are charged with identifying at least one planning group for their jurisdiction, with consideration given to use of existing processes and planning bodies. Several options exist as grantees consider whether to create a new structure or modify an existing one. These include:

- use an existing planning body instead of creating a new structure;
- use the existing group as a foundation for building a more focused prevention planning effort;

- create a specialized planning group or groups under the umbrella of a larger pre-existing planning body;
- create a new planning group, if the existing entities are not easily modified, adaptable, or appropriate to the prevention planning effort.

Decisions to guide determining whether to modify or create a new group include: effectiveness of the existing planning body; its ability to incorporate a focus on HIV prevention (e.g., competency of staff, members with prevention issues); amount of modification required; and the means by which the prevention group will coordinate with other planning efforts.

The authority provided to the planning group should be explicitly communicated. The framework for determining this authority structure is found in the CDC *Supplemental Guidance*, which instructs grantees to develop a “Comprehensive HIV Preven-

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*“It’s difficult to know how to integrate people into an existing group. We’ve spent a year talking about doing it. There may be hidden resistance. Turf issues are a problem. And change, even good change, is scary.”*

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tion Plan, jointly developed by the grantee and the HIV Prevention Community Planning group(s), which includes specific, high-priority HIV prevention strategies and interventions targeted to defined populations to be supported with HIV prevention cooperative agreement funds.”

### 1.3.2 Develop Criteria for Membership

An open and fair mechanism for forming the membership of the planning group should be established through criteria for identifying, nominating, and selecting participants. Criteria should guide decisions in determining individual members as well as the composition of the entire planning group. Grantees should establish these criteria, up front, in order to provide the framework for a rational and thorough selection process. Criteria outlined below include: CDC criteria, additional qualifications standards, and ability of members to carry out membership roles and responsibilities.



1.3.2.1 CDC criteria. CDC has established specific criteria for membership in the planning group. Members should:

- reflect the characteristics of the epidemic in the jurisdiction (in terms of current AIDS cases, persons with HIV infection, and those at highest risk for HIV/AIDS); CDC outlines the following criteria: age, race/ethnicity, gender, sexual orientation, geographic distribution, HIV exposure status and category;
- be able to articulate and have expertise in understanding and addressing the specific HIV prevention needs of the populations they represent; and
- include scientific experts; service providers; representatives of organizations, such as state and local health departments and state and local education agencies; other relevant governmental agencies (substance abuse, mental health, corrections); experts in epidemiology, behavioral and social sciences, and evaluation research; and health planning representatives of nongovernmental and governmental organizations providing HIV prevention and related services (e.g., STD, TB, substance abuse prevention and treatment, mental health services, HIV care, and social services).

Of particular importance is undertaking recruitment efforts that ensure that the planning group includes socioeconomic and at-risk groups that are underserved by existing HIV prevention programs (see Section 1.3.3.2 "Ensuring Inclusiveness and Representation in the Nomination Process," below). Recruitment should address both selection of members who are representative as well as ensuring the capacity of all members to participate fully.

These overarching CDC criteria should guide the selection process, although additional assessment of candidates for membership should take place so that the most appropriate individuals are selected. Grantees can develop assessment standards, with input from local and state public health authorities, leaders of affected communities, and others.

1.3.2.2 Qualification standards for individual members. Consideration may be given to qualification standards of members, including the level and type of experience and the resources that each member (as represented by an organization or individual) can bring to the planning group (CDC, 1993). Resources can include:

- funds, services or service capacity, facilities, or materials;
- clients;

- authority or influence over resource allocation decisions;
- technical expertise and skills;
- skills/experience in coalition development and maintenance, leadership, and communication skills;
- information;
- access to other needed resources;
- legitimacy with particular sub-groups; and
- legitimacy with key community decision-makers.

In considering these standards, grantees should be aware that a planning body can have both "individual" and "organization" slots, wherein candidates are selected based upon qualifications of the individual or the agency with which they are associated. For example, informal community leaders may be on the planning body as representatives of the community but not any particular agency or organization.

In determining organizations that should be represented in the planning group, various types of individuals can be designated. Higher level representation—such as executive directors or program managers—symbolize the priority that members and their organizations place on the effort. In addition, senior individuals can make more decisions or commitments. Frontline staff, however, are needed as well. They are often singular in possessing critical information and relevant skills. They also may have the time needed to undertake specific task assignments, and can provide greater continuity of representation (i.e., some groups send a variety of staff to meetings as they are available).

Determining the types of individual members to recruit is additionally complicated given that the work of the planning group will vary over time. Particular sessions may be most appropriate for executive level staff, whereas other meetings may benefit from the input of frontline staff. In selecting individual members, grantees should consider that most also serve as staff in community agencies that bring a range of expertise through other staff. Consideration can be given to the potential contributions of staff in those agencies, whose participation on an as-needed basis, in lieu of the primary member, may be desirable. Most organizations are aware that the agenda changes and that they may need to send different staff at different times.

1.3.2.3 Ability to fulfill the basic roles and responsibilities of membership. This can be broadly defined as:



- ability to represent the perspective(s) for which they were selected to participate (e.g., an organization, discipline, affected community);
- willingness to share responsibility and authority in a group context;
- willingness to participate fully, including commitment to the task and effort;
- willingness to provide substantial time commitment;
- ability to assist in reducing logistical barriers;
- ability to provide constructive feedback in the planning process; and
- ability to keep key people in their home organization or community informed about the planning group and its efforts.

1.3.2.4 Composition of the full planning group. It is critical to provide a balance of perspectives, opinions, expertise, and skills in the planning group. No specific sector should be in a position to dominate the planning and decision-making process by having greater representation on the planning group.

An important consideration is to determine the ideal number of planning group members. As reflected in the "Notes from the Field," later in this chapter, there is no magic number of members. Grantees have created planning groups that are anywhere from 10

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*"We hope we get nominations of people we've never heard of, never seen before."*

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to over 50 members in size, depending on their needs and the scope of representation and inclusiveness they have identified.

Large states and populous areas with multiple constituencies will obviously need to broaden their membership to include the range of important perspectives. However, too many members may result in an ineffective and unmanageable planning group effort. Group dynamics can be negatively affected by having too large a number of participants, and logistical issues (e.g., identifying acceptable meeting times) can become burdensome.

Large planning groups can nonetheless carry out their work effectively by establishing such mechanisms as a core executive group, committees and task forces, and other working factions. (See Chapter 2 on organizing ideas that will facilitate the work of the planning group.)

### 1.3.3 Identify Members: Nomination, Inclusion, Invitation, Selection

The process of identifying a balanced, representative, and appropriate planning group involves several important steps. This process should be based upon previously-established membership criteria and desired composition of the full planning group.

As a practical matter, determining membership is a several-staged process. First, a pool of candidates is identified. Second, the best candidates are discussed and narrowed down to a nomination pool. Third, invitations are extended. Fourth, candidates who accept are confirmed, although some candidates may not be selected if there are more willing candidates than there are slots on the planning group.

Identifying members can be coordinated through a membership committee. This group can be the same group established to oversee establishment of the planning group process. Tasks of this committee might include: identifying a pool of candidates; discussing and determining essential qualifications; interviewing candidates to assess their qualifications; explaining the purpose of the planning group to affected communities; and determining those candidates who should be formally invited and selected. It is critical for the membership committee itself to be broadly representative so that a significant range of involvement is obtained in identifying potential members. Table 1-2 presents some sources for potential members.

1.3.3.1 Nomination. Identifying and nominating potential members can occur through several approaches, a general call for nominations may be issued by the grantee to community groups, agencies, and individuals. Alternatively, the "snowball" method can be useful, wherein interviews are conducted with individuals who represent organizations and communities in order to gather names and information about potential candidates; when the same names appear repeatedly (i.e., snowballing), the list may be complete (Feighery and Rogers, 1990).

Many more potential members may be identified during the nomination process than there are available spaces on the planning group's roster. Decisions and difficult choices will have to be made by the membership committee or some other party. However, candidates who are not selected for the planning group can be used in some other manner. Aside from the formal planning group process, other opportunities to participate will exist, such as serving as a special source of expertise on a specific issue or as-

sisting with the needs assessment process in some manner (e.g., as a focus group member or key informant to be interviewed during data collection).

**1.3.3.2 Ensuring Inclusiveness and Representation in the Nomination Process.** In striving for inclusiveness and representation, grantees will need to develop specific strategies to identify individuals or organizations that are representative of low socioeconomic groups and groups that are underserved by existing HIV prevention programs. For a variety of reasons, such groups and their representatives may be hard to identify or gaining their trust may be difficult. Approaches can include the following:

#### **Table 1-2: Nominations for the Planning Group**

In nominating members for the planning group, consider the following sources:

- state and local health departments
- members of existing coalitions
- community-based organizations
- AIDS service organizations
- racial and ethnic minority organizations
- gay/bisexual organizations
- voluntary grassroots organizations
- people with HIV infection
- people with AIDS
- schools
- individuals working with injection drug users
- substance abuse treatment clinics
- correctional facilities
- individuals with maternal and child health experience
- religious organizations
- hospitals
- health care professionals
- primary care clinics
- selected experts in various other fields (e.g., social and behavioral scientists, evaluators, health educators, sex educators, health planners, grant writers, epidemiologists)

- Contact known leaders and key spokespersons in targeted communities, as well as less visible and informal key informants. While these individuals may also be candidates for membership, they should also be asked to identify other potential candidates. Their ability to do so can indicate their knowledge of the community.

- Charge specific racial and ethnic minority organizations or minority coalitions with nominating and/or selecting a given number of candidates.

- While there will be a wide range of persons and groups to contact, some parties in particular should be sought out when conducting outreach (e.g., religious leaders, organizations representing gay/bisexual men of color).

- Making contact with informal key leaders is particularly important given that well-known spokespersons or agencies may be more in touch with the mainstream perspective than with their own community.

- Make an assessment that an organization is truly representative of low income and underserved groups. Assessment criteria might be based upon one or more of the following: make-up of the agency's staff; make-up of the board of directors; staff and board skills and experience in working with the community; mission statement and program activities of the organization.

- When identifying people with HIV infection and AIDS to serve as members, consider working directly with case managers or other frontline service staff. These staff are usually the most familiar with clients and can identify those most qualified (e.g., articulate, accessible) to serve. Also, consider identifying backup candidates in the event that participation becomes a problem due to illness or medical crisis.

- Some individuals and agencies from low income communities may be reluctant to participate. Reasons might be past involvement in ineffective coalitions, cynicism about the value of the effort, or misunderstanding of the role of the planning effort. Ask if such reservations exist and then address them directly (National Cancer Institute, 1992).

- Repeat special recruitment efforts on an ongoing and as-needed basis. This is not just an initial activity.

- Hold public hearings at sites located in underserved community sites. Individuals who attend may turn out to be ideal candidates for membership in the planning group.

1.3.3.3 Invitation. Generally, invitations to participate should occur only after the initial selection of nominees has been completed by the nomination committee or group. Invitations can also be coordinated through a central body or individual so that the same message and overview is given on the purpose of the planning group and expectations of members.

Invitations should also be written. Less confusion is likely to occur when details are laid out on paper. However, reliance on written invitations alone is not suggested. Everyone is overwhelmed with paperwork. A general letter of invitation, even a personalized letter, might get lost or not be taken as seriously.

Verbal contact through a phone call or a meeting constitutes a critical means for securing involvement of key individuals and is an effective way to approach nominees initially. Such personal contact also conveys the sense of importance attending participation in the planning group. In the personal contact, the following items are important to address:

- Identify yourself and the purpose of your call. If the nominee is not well-known or may be likely to resist participating, consider having the invitation conveyed by a business, community, or political colleague who knows the nominee or affected community. Such one-to-one contact between colleagues is a well-accepted practice and an effective way to convey the importance of the effort, especially for busy individuals who may be reluctant to commit time to the effort.
- Outline the goal of the planning group. This is likely to be very general since the planning group's goals are not likely to be developed until the body has actually met.
- Explain the reason you are inviting the individual (i.e., what skills, expertise, perspectives they can bring to the group).
- Ask the invitee if they have concerns or reservations about the planning group and then address them directly.
- Specify expectations about the roles and responsibilities that membership conveys, including tasks, expectations regarding participation, and tenure of membership.
- Inform the candidate that he/she may not actually be selected because invitations are being extended to more individuals than there are slots. However, also

emphasize that opportunities other than planning group membership exist in order to participate in the planning process.

1.3.3.4 Selection of Members. Selection of members may involve little more than confirming that invitations have been accepted. However, when a larger pool is invited than can be actually selected, decisions will have to be made on actual selections. This is the responsibility of the nomination group. Its decisions should be guided by the principles of inclusiveness, representation, and parity, along with consideration of the specific qualifications of individual candidates, balance in the group, and the ability of individual candidates to fulfill their roles and responsibilities.

## 1.4 ENSURING PARITY: MAKING PARTICIPATION POSSIBLE, ORIENTATION, AND TRAINING

Once members have been selected and brought on board, provisions should be made to ensure that parity exists among the membership (i.e., that all members are equally prepared to participate fully in the process). Technical assistance and capacity development needs should be actively and openly identified by the planning group in its early stages—and throughout its existence.

Training needs are likely to exist for some, if not all, members. Such training may be critical to bringing all members up to speed. All will have a valid voice but perhaps not the skills or capacity to participate.

Such capacity training is needed because some sectors and individuals come from communities that have

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*"We need to make sure that those brought to the table are able to participate in a meaningful way."*

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experienced significant disempowerment. Lack of resources and powerlessness can effectively serve to block access to information and skill development opportunities. For example, individuals from lower socioeconomic levels may have little faith in their ability to affect change; frequently lack knowledge and information to enable them to participate in discussions fully; and have fewer leadership, organization, and professional skills (Wandersman, 1981).

Equally important is the need to identify, or take an inventory of, the assets available from communities at need. Their skills can, in turn, become the focus of training for other group members.

#### 1.4.1 Making Participation Possible

Participation for all members entails participation costs, which generally involve time, money, and feasibility. For low income populations and persons with HIV/AIDS, participation may be particularly difficult. Organizations representing such populations may face more severe time constraints because they often have small staffs; the absence of even one staff mem-

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*"You're not starting in a vacuum.  
Remember that some planning  
activities have already occurred.  
Build on this experience,  
both good and bad."*

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ber may cripple the agency's regular activities. Staff may not be able to take the time because they cannot afford to lose income from their jobs. Difficulties may also be faced in securing transportation to meeting sites.

Planning groups should consider options to enhance participation for members who require assistance, such as transportation subsidies, scheduling of meetings at convenient times, and minimizing the number of meetings so that all group members can participate fully.

#### 1.4.2 Orientation

Orientation usually occurs at the beginning of the planning process, but can be ongoing to keep members up-to-date on information, such as technical data on prevention strategies. Consideration should be given to making attendance mandatory, *with a defined number of allowable absences*.

An initial orientation typically involves introductions, laying out the process, rules, expectations, and mission/goals for the planning group, including review of CDC program guidance. Other items covered might be the time frame for action; major activities to undertake; and expectations for members. Orientation provides an opportunity to identify and address any lack of clarity about the overall mission and focus of the group.

While the process of orientation involves delineating existing rules and structures that have been de-

veloped by the grantee, this is also the time to identify those activities that are to be carried out by the planning group in setting up a process for its deliberation and planning.

Orientation is also the time to identify and minimize situations that can disrupt participatory planning. For example, liaisons among factions of members who already know each other can result in alienation of other members. One approach to use during the orientation—and subsequently during planning meetings—is to use an alphabetical seating chart for members. This can also be helpful to the co-chairs in helping them readily identify members and get a sense of who is in attendance.

Other situations that can hinder participatory planning include using jargon or other inside information not familiar to new members, and failing to openly and fairly use the group process to discuss and resolve issues. Both result in exclusion of participants from access to all information and can hinder the sense of group purpose. Orientation can be a time to encourage members to seek out new perspectives; stress the importance of sharing information openly; define jargon terms and technical information in writing; and emphasize the importance of directing all efforts toward the group (National Cancer Institute, 1992).

#### 1.4.3 Training

Training can occur in small or large group settings or one-on-one. Sessions can be convened as a component of regular planning group meetings or as separate events.

Advantages to conducting training as a part of regular planning group activities are that all members are likely to be present; individuals will not feel as if they are being singled out; the training can be identified by members as more readily relevant to their planning responsibilities; and members are not required to devote extra time to training. This last consideration is particularly important given that members from low income communities may have limited time or resources to attend training sessions. The disadvantages are that critical time is spent on training instead of focusing on the planning activity.

Alternatively, special training sessions may be scheduled to enable members to focus more attention on the training process. However, members most in need of training may feel singled out to receive such training and may actually resist participating. Approaches to overcome this problem include presenting training options to the full group so members can

voluntarily sign up for training they think would be helpful to them. Training can also be offered to the full group as a group activity so that no member is excluded.

**1.4.3.1 Training Topics.** Training needs will vary among group members. Topics to consider are as follows:

- Training on group process. This would address group decision-making, how to participate in a group process effectively, use of formal and informal rules of order and procedure, review of committee and subcommittee processes, and roles and responsibilities of individual members.
- Training on diversity issues. Variations will exist in member backgrounds and perspectives. Diversity will exist on the basis of race, ethnicity, gender, age, socioeconomic status, educational level, and sexual orientation. Areas for particular attention in addressing diversity include: process (i.e., establishing a common process framework to address variations in planning and decision-making among government agencies, community organizations, for-profit, nonprofit, and racial/ethnic communities); language (i.e., cultures vary in their use of language in communicating and working together); etiquette (i.e., addressing differences in how members interact and express opinions in order to avoid conflict).
- Training on discipline perspectives. Members are likely to come to the planning group equipped with

varied backgrounds in HIV prevention, public health, health education, understanding of community interventions, and special disciplines (e.g., epidemiology, behavioral and social sciences, evaluation, sexuality, substance abuse prevention). Enhanced knowledge in any of these areas can result in the improved understanding of HIV prevention needs and the design of effective interventions.

- Training on public health principles. This area is of particular importance given that the participatory planning process will, for most entities, be a departure from existing decision-making models, in which the public health authority historically has centralized planning within the public agency's staff. Thus, parties new to the process may not be fully aware of the range and purpose of HIV prevention strategies (i.e., public information, HIV counseling and testing, community based, health education/risk reduction, prevention case management). In some cases, members may actively resist existing public health interventions (e.g., opposition to HIV counseling and testing because of a perception and belief that it is an ineffective prevention strategy).
- Training on HIV/AIDS. Not all members will necessarily be fully acquainted with HIV/AIDS prevention issues or fully aware of the history of HIV/AIDS prevention initiatives or the results of past efforts. Elected officials, for example, may not have experience with public health, particularly HIV/AIDS, but might be crucial additions to the planning group.

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# Notes from the Field:

## Ensuring Community Participation

### OVERVIEW

**T**he state AIDS directors described in detail the actions that are being taken in their states to prepare for HIV prevention community planning. Most states have convened advisory groups to advise them on organizing the planning process and nominating committees to help select members for their community planning bodies. The approaches to participatory planning and the mechanisms developed to ensure inclusiveness, representation, and parity are varied.

All states expressed concern about getting the right people in the community involved in the planning process. Some states indicated they had "done it right" in the past by ensuring broad community participation and representation on standing advisory committees and task forces, and Title II planning consortia. Other states indicated that although they had sought community input and participation in previous planning activities, they did not feel they had been inclusive enough.

The respondents agreed that HIV prevention community planning challenges the states to establish a planning process that ensures representation, inclusiveness, and equal participation of membership.

### ORGANIZING THE PLANNING BODY: PLAN TO PLAN

**G**et help in getting started. Form an advisory group. Many state AIDS directors discussed at length the time-consuming and complex work of getting the community planning process started. One of the first steps for many of the states convening an advisory group to help plan the planning process. There was great diversity among states in the size, structure, function, and membership of these groups.

The size of the advisory groups ranged from 10 members in one state to 55 in another. Many states

used existing models of standing advisory committees and task forces to set up the structure for their prevention planning advisory groups. Most established a centralized committee or group on the state health department level; others decentralized the process by establishing advisory working groups across the state or by giving local health departments autonomy in convening their own advisory and planning groups locally.

*Use advisory groups to plan for planning.* The advisory committees and working groups convened have very important functions that may vary from state to state. One state AIDS director referred to the state's advisory group as a "logistical planning team." The function of this team is to draft agendas, select facilitators, and manage the nomination process for the statewide community planning group. In another state, the advisory group is charged with developing a structure for the planning group, nomination forms, and selection procedures for community planning body members. As one respondent indicated, "You have to do your homework and develop a structure for people to work within."

### ORGANIZING THE PLANNING BODY: ESTABLISH A COMMUNITY PLANNING GROUP STRUCTURE

**T**he states described a variety of models for establishing their HIV prevention planning group structures. The models range from centralized statewide planning bodies to regional planning groups to county-based community planning groups at the local level. One model used by more than one state designates independent regional planning groups to produce regional HIV prevention plans. Each of the regional groups elects representatives to a state planning body, that will then coalesce regional plans into one statewide plan.



Other states are using a more centralized approach by setting up one statewide community planning committee or task force on HIV prevention. In one state, a key agenda item for this planning group will be to determine whether there should be regional planning groups or just one central planning committee.

### Prevention Planning Profile

In Texas, "planning to plan" has resulted in working groups with members from across the state who have expertise in planning and represent community and regional diversity. They include CBOs, CARE consortia members, local health departments, and frontline workers who are charged with developing draft guidelines and documents on by-laws, membership criteria, voting rules, committee structure, nomination and selection process, barriers to compliance, roles and responsibilities, needs assessment, and training for review and revision by the regional community planning groups once they are formed.

#### Summary of Possible Advisory Group Functions:

- Develop planning group structure.
- Draft agendas for planning group.
- Draft by-laws.
- Select group facilitators.
- Plan and implement the nomination process.
- Select planning group members.
- Identify roles and responsibilities.
- Plan group orientation and initial training.

Yet another model involves a decentralized approach where community planning will occur on the county level and be coordinated through the efforts of local health departments. Prevention plans will be developed locally and not submitted to a central statewide planning body. Regardless of which approach was selected, the states recommended that the process be community-based and not health department driven.

### Prevention Planning Profile

Connecticut's planning committee will have 30 representatives but not all the slots will be filled through the nomination committee process. Some slots will be filled by planning committee members after their initial meeting. The state is interested in increasing access for input of people usually not asked to participate in a planning process, e.g., inmates and active IV drug users.

## ORGANIZING THE PLANNING BODY: ESTABLISH THE NOMINATION PROCESS

Irrespective of planning group structure or model, one of the first critical tasks for each state has been to establish a process for nominating and selecting members for the HIV prevention community planning groups. States have been thoughtful, creative, and strategic in their nomination processes. They are committed to ensuring that the nomination process would be a full and open process that would result in "getting the right people to the table."

One respondent stressed the importance of involving new people in the community planning process. She stated, "We hope we get nominations of people we've never heard of, never seen before."

*Designate a nominating committee.* Many state health departments have relied on their advisory groups to help with the nomination process. In some instances, the advisory groups have designated smaller nominating committees; in other cases, the state has set up an independent nominating group to avoid any potential conflict of interest.

*Establish selection criteria for planning group representation.* The state health departments have required their advisory groups and nominating committees to adhere to the selection criteria for nominees set forth in the CDC *Supplemental Guidance* for planning group representation. In one state other criteria for nomination included: people who are HIV positive; people with AIDS; frontline providers; and consumers. In addition, other criteria mentioned included people with access to networks; and people who were seen as being well-organized and effective at getting things accomplished.

A state AIDS director indicated the nominating committee's commitment to building a diverse planning group based on geography, race, sex, providers, and non-providers. Less than one-third of the committee will be from local and state health department staff and two-thirds will represent the community. In this state no one from the health department AIDS or STD staff can be nominated to the planning committee.

tee. In some states, advisory group members are precluded from applying for membership on the planning committee; in others they can be nominated and selected.

**Establish procedures to ensure a full and open nomination process.** Procedures and plans for recruiting planning committee members varied among the states. However, all were developed in the "spirit of the *Guidance*" requiring efforts to ensure a full and open nomination process. One state viewed "proactive recruitment" as the key to getting the right people to the table. It searched for the "right people" by using regional staff, its widely representative and diverse advisory group and by disseminating information throughout the state through direct mail to CBOs, CARE consortia members, local health departments, frontline workers, and others.

Some nominating committees are "blanketing their states" with calls for nomination. One advisory group designed and approved an application form that will be sent out to a wide array of individuals throughout the state for the purpose of nominating members to the planning group. After the nominations are returned ten members from the advisory group will review all of the applications for membership.

Another state used a more targeted effort to ensure an open nomination process, which previous planning efforts did not have. Using a mailing list from the state health department, the call for nominations went out to over 1,800 names including individuals who are HIV positive, community-based organizations, health care providers, and others. The nomination form described the purpose of the planning process, requirements to serve on the committee, and desired areas of expertise and representation.

In some states, the nominating committees will review and screen all nominations and select all representatives for membership on the HIV prevention community planning committees. In other states, the advisory groups will nominate individuals for some

but not all of the positions available. The planning committee members will have the responsibility of filling the remaining positions.

### Lessons Learned About the Nomination Process:

- Be proactive in seeking the right people.
- Clearly define areas of expertise and experience required.
- Include specific questions on the nomination forms with respect to race, sexual orientation, ethnicity, gender, etc. to ensure diversity of representation in nominations.
- Recruit committee members who have expertise in community organizing, community development, public health, epidemiology, health education, and social marketing.
- Plan sufficient time for the nomination process.
- Recognize that nominees who do not get selected are a powerful resource; keep them informed of and involved in the process.

Table 1 summarizes the models or approaches taken by nine states in establishing their community planning bodies. It indicates for each state, where appropriate, the number of advisory group or nominating committee members, the type and number of community planning committees, and the establishment of any additional supporting committees or groups.

### ASSURING INCLUSIVENESS, REPRESENTATION, AND PARITY

**M**ake sure people in the community are represented in the planning process. In discussing the challenges posed by representation, one respondent stated, "Local clients must have a voice at the planning table. If they can't have a voice the nurses, social workers, and health educators must be able to express their concerns on the clients' behalf. There are a variety of ways to make sure people have representation in the planning process without actually being at the table."

All states expressed the importance of establishing community planning groups that will reflect the diversity of the community. A state AIDS director said, "We have multiple representation on our group...it looks like our state, looks like our epidemic."

#### Prevention Planning Profile

In California, individuals who were nominated but not selected for the planning committee received a letter from the Office of AIDS indicating it hopes to involve them in the planning process on an ad hoc basis. They will be kept informed and receive regular communication on planning efforts. The state believes it is important to keep individuals engaged who have expressed an interest.

*Work actively to include those in the planning process who have previously been excluded.* These challenges of inclusion are not always easily met. When an established consortium in one state was planning to do more outreach to include communities of color, including gay men of color, the process of including them in the consortium was described as "a year of talking about doing it." The state AIDS director said, "It's difficult to know how to integrate people into an existing group. There may be hidden resistance. Turf issues may be a problem. And change, even good change, is scary to people."

*Create a level "playing field" for all group participants.* Another state identified the challenge of parity as the creation of a level "playing field" in which all participants feel free to speak up and actively participate in the workings of the group. Ensuring parity means that everyone on the planning committee has an equal opportunity to participate and to be heard "at the table." It also requires that all participants

### Prevention Planning Profile

Massachusetts has developed a community planning committee that will be comprised of 40 members. It will include CBOs, people living with HIV, state health department representatives, and local health and government officials. The group will be co-chaired by a representative of the state health department and a CBO representative to be chosen by group members. Special efforts are being made to find consumers who represent the highest-risk populations. The state believes these individuals bring a special perspective to bear on the needs of those affected populations at highest risk.

have parity of information and skills, according to one respondent, in order to participate meaningfully in the dialogue and decision-making. Several state AIDS directors mentioned the importance of ongoing technical assistance and training for all community planning committee members so that they are all equipped and supported to do their job.

**Table 1: Summary of HIV Prevention Community Planning Approaches by State**

<p><b>California</b></p> <ul style="list-style-type: none"> <li>• 12-member advisory group</li> <li>• 55-member statewide planning group</li> <li>• technical advisers group</li> </ul> <p>(based on Title II 3-tier model)</p>	<p><b>Connecticut</b></p> <ul style="list-style-type: none"> <li>• 14-member nominating group</li> <li>• 30-member statewide planning committee</li> </ul>	<p><b>Illinois</b></p> <ul style="list-style-type: none"> <li>• 17-member HIV Advisory Group reassigned to serve as nominating group</li> <li>• 35-member statewide planning committee</li> </ul>
<p><b>Massachusetts</b></p> <ul style="list-style-type: none"> <li>• 45-member preliminary advisory group</li> <li>• 10-member selection committee</li> <li>• 40-member statewide planning committee</li> </ul>	<p><b>Michigan</b></p> <ul style="list-style-type: none"> <li>• 25 member "plan to plan" group of local health departments and community based organizations</li> <li>• 8 regional planning groups</li> <li>• statewide planning group</li> </ul>	<p><b>Minnesota</b></p> <ul style="list-style-type: none"> <li>• 15-member statewide Task force on HIV Prevention</li> <li>• 8 regional working groups on specific issues, e.g. women, rural populations</li> </ul>
<p><b>Oregon</b></p> <ul style="list-style-type: none"> <li>• 34 county level planning groups</li> <li>• coordination by 34 local health departments</li> <li>• no statewide planning group (to date)</li> </ul>	<p><b>South Carolina</b></p> <ul style="list-style-type: none"> <li>• 25-member advisory planning committee</li> <li>• 7-member nominating committee</li> </ul>	<p><b>Texas</b></p> <ul style="list-style-type: none"> <li>• 25-member working group</li> <li>• nominating committee</li> <li>• 11 regional planning groups</li> <li>• statewide planning group</li> </ul>

## ESTABLISHING CRITERIA FOR REPRESENTATION

This list was generated by synthesizing criteria for representation set by several states. All states reported using the *Supplemental Guidance* for selection criteria. Additionally, they also were looking to identify committee members who are:

- team players
- problem solvers
- able to see the big picture.
- have HIV/AIDS
- frontline providers
- participants who have recently (within last two years) met the case definition of AIDS
- consumers
- providers
- people with access to networks
- people seen as well-organized and efficient
- experts in HIV prevention

- personally involved in risk reduction activities
- from diverse geographic areas in the state
- from different cultural backgrounds
- from diverse sexual orientations

### Lessons Learned About Representation, Inclusiveness, and Parity:

- The process can always be more inclusive. States should avoid internal selection processes if they want to be inclusive.
- Representation in the past has often been based on geographic region. This might have seemed like a good idea at the time, and the right thing to do, but there needs to be more than geographic representation from around the state.
- Local health departments have often sought input from "community leaders." Some of these leaders were not always the opinion-makers or gatekeepers. The right people from the community need to be identified through a consensus-building process.
- Make sure there is active participation from target population(s).

# Handouts

Handbook

## Participatory Planning: How Do HIV Prevention Programs Benefit?

Participatory planning is built upon a broad range of input and community knowledge. As a result, it can improve HIV prevention programming by providing:

- A more complete picture of community HIV prevention needs.
- Enhanced access to hard-to-reach populations.
- Better targeting of programs to specific populations.
- More comprehensive program planning.
- Enhanced coordination between planning efforts and subsequent HIV prevention delivery.
- Less duplication and fewer gaps in services.
- A broad-based understanding of and support for HIV prevention needs.
- Greater community ownership of and commitment to prevention programs.
- Increased appreciation by the community.
- Increased credibility with affected communities.
- Increased community understanding of and support for health department efforts.
- Investment of resources by other community partners.
- Increased utilization of services.
- An increased voice for the community in program planning and development.
- Improved capacity of participants to assess needs and plan programs.
- An opportunity to develop programs that are more complementary to community desires.
- Involvement of many different community sectors.





## Nominations for the Planning Group

In nominating members for the planning group, consider the following sources:

- state and local health departments
- members of existing coalitions
- community-based organizations
- AIDS service organizations
- racial and ethnic minority organizations
- gay/bisexual organizations
- voluntary grassroots organizations
- people with HIV infection
- people with AIDS
- schools
- individuals working with injection drug users
- substance abuse treatment clinics
- correctional facilities
- individuals with maternal and child health experience
- religious organizations
- hospitals
- health care professionals
- primary care clinics
- selected experts in various other fields (e.g., social and behavioral scientists, evaluators, health educators, sex educators, health planners, grant writers, epidemiologists)



# Chapter 2

## Valuing and Managing the Community Planning Process

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2.2 Valuing the Group Process	2-1
2.3 Setting Expectations for the Planning Group	2-2
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The Community Planning Process	Community Planning Tasks	Additional Resources
1. Ensuring Community Participation	4. Developing an Epidemiologic Profile	9. Resources for HIV Prevention Community Planning
2. Valuing and Managing the Community Planning Process	5. Assessing and Setting Priorities for Community Needs	
3. Conflict of Interest and Dispute Resolution	6. Setting Prevention Program Priorities	
	7. Selecting Among HIV Prevention Interventions: Theoretical Basis, Effectiveness, and Cost-Effectiveness	
	8. Evaluating the Community Planning Process	



# Chapter 2

## Valuing and Managing the Community Planning Process

### 2.1 OVERVIEW

Establishing the planning group structure, as discussed in Chapter 1, is the foundation for the planning process. This chapter outlines critical considerations and steps that will move the planning effort forward.

First, the planning group must develop a sense of ownership in the group process. This requires a shared vision and trust among members. The group must then set expectations for itself in terms of its goals and roles/responsibilities for members and grantees. The next section of the chapter outlines the importance of setting expectations for the group in terms of its goals and roles/responsibilities for members and grantees.

#### Definitions

*Planning process*—The steps taken and methods used to gather information, interpret it, and produce a plan for rational decision-making.

*Valuing the process*—Developing a sense of group ownership and belief in the community planning participatory process and recognizing the importance of broadening the impact beyond group activities to the community at large.

*Group process*—The way a group behaves and functions and its members interact.

*Accountability*—Devising a framework for how a group and its members will be responsive and responsible to itself and the community as it carries out its mission.

Once this broad mission has been set, the group must establish mechanisms to monitor and guide the planning process. The last part of this chapter outlines such mechanisms. They include: developing a workplan and ground rules for participation in the planning process; establishing channels of communication; decision-making procedures; and operating procedures on the group's functioning (i.e., developing objectives and a workplan, co-chairs, officers, committees, and meetings). Finally, groups must guard against losing momentum or getting stuck. Suggestions to avoid these pitfalls are discussed. At the end of the chapter there is a section entitled, "Notes from the Field: Valuing and Managing the Community Planning Process." These "Notes" are a synthesis of major findings from interviews conducted with state AIDS directors and other project area staff regarding their experience with valuing and managing the community planning process.

### 2.2 VALUING THE GROUP PROCESS

Members need to believe that group process works as a planning and decision-making mechanism. They also need to value the process. This is based upon a shared vision, mutual trust, willingness to work together, and the belief that the process is an effective way to make sound decisions.

#### 2.2.1 Sharing the Vision

In order to establish a group vision, a common vision first needs to be held by the individual members of a group. In this instance, the individual members need to have a common vision of reducing the incidence of HIV within the community. Planning group members need to be willing to act together to

address this mutually identified concern. They also need to believe that joint action will produce results. This sharing of a vision implies that members are willing to work together to achieve the goal of the planning group, while understanding that each member may bring a different agenda to the collaboration.

Realizing a shared vision begins with understanding that there are different agendas and needs among

### *“Community planning deserves to be done well.”*

members. The challenge for members is to recognize and appreciate these differences without losing sight of the group's goals.

One way to begin the process of developing a shared vision is to have each member verbalize or write down their vision. Differences can be discussed and worked out, and adjustments made along the way. For example, the co-chairs can ask individual members to assess their reasons for involvement in the planning group in terms of:

- the relevance of the group's goal to the mission of their agency and to their activities within the community;
- the fit between the needs of the population(s) the group will target and the needs of the population(s) they serve;
- what they or their agency can contribute to the group; and
- how they will benefit from participating in the group.

#### 2.2.2 Developing Trust

With the creation of any group, establishing trust is integral to ensuring effective group functioning and open communication. When trust is not present, it becomes virtually impossible to move forward. Yet, trust is often overlooked as too “touchy-feely” an issue for many groups. Trust is one of those slippery concepts that makes many groups feel uncomfortable and vulnerable.

In a group where members fail to trust each other, problems can occur, such as poor communication, chaotic functioning, an inability to make decisions, come to agreement, resolve problems, or get work done. An absence of trust can lead members to ignore, withhold, and distort important information and ideas that they believe will increase their vulnerability with the

group. They can be unreceptive to and even suspicious of the group's goals, suggestions for reaching goals, and methods for assessing accomplishments and resolving problems.

Building and maintaining trust takes time and requires risk-taking. Group members must be willing to share information, rely on each other, respect and acknowledge opinions, recognize and appreciate differences, and work together to accomplish goals. To do this, group members need to:

- Meet commitments and follow through. Members need to act on what they say they will do in a timely way.
- Show sensitivity to other members' needs and interests. Listening to what other members have to say and trying to understand and appreciate their points of view demonstrates respect for other individuals and their ideas.
- Be open about members' actions and intentions. Holding secret meetings or closed-door sessions for selected group members only fuels suspicion and mistrust. Sharing information and keeping others up-to-date avoids surprises within the group and helps members to feel informed and comfortable.
- Honor the ground rules and decision-making procedures set by the group. Trying to get around agreed-upon rules and procedures can create a major disturbance to the group process and deter the progress of the group toward realizing its mission or goals.

Maintaining trust over time takes the commitment of the entire group. Groups need to develop a “we” mentality as they work together to accomplish mutual goals.

## 2.3 SETTING EXPECTATIONS FOR THE PLANNING GROUP

Once the HIV prevention planning group has been set up, the group needs to establish clear and broad goals for the process and determine roles and responsibilities for the grantee and the planning group. This is setting expectations. Key questions include: What is the purpose of the group? What needs to get accomplished and by whom? Who will be responsible for specific tasks? What are the individual member roles? How will the group share leadership? What impact does the group hope to have on the community?

This critical step is often short-changed in a group planning process because it requires a significant commitment of time, can introduce differences of opinion early on, and can make group members feel uncomfortable. Setting expectations, however, will result in greater clarity of purpose for the planning group, increased understanding of individual member needs and concerns, establishment of a shared vision, and enhanced cohesion and functioning of the group.

It is important to recognize that this process is not static. Given the changing nature of the HIV epidemic, as well as the natural changes that occur in any group (e.g., member attrition, member agency shifts in direction or time commitments), adjustments in expectations for both the group and for individual members will occur along the way.

### 2.3.1 Establishing Goals

A goal is a broad statement about the long-term outcome or ultimate purpose of a program or activity. The goal for the HIV prevention planning process, as established by CDC, is to develop a comprehensive HIV prevention plan for a project area that will identify specific HIV prevention strategies and interventions that are responsive to high priority, community-validated needs within a defined

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*"Participants need to know why they are on the committee. Some of them may serve more than one role. This should be defined in the selection process. How people present themselves is important. They need to be clear about whom they represent."*

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population(s). This is a shared goal for all planning groups across the country, although it is expected that different project areas will develop quite different plans to achieve this goal. Planning groups are encouraged to establish additional goals appropriate to their communities.

### 2.3.2 Defining Roles and Responsibilities

The group needs to develop a process for completing its work. This includes defining roles and responsibilities (e.g., assign accountability, ensure completion of tasks, share/distribute workload and

authority among members). CDC has outlined basic roles of all parties involved in the HIV prevention community planning process—the grantee, the planning group, and CDC—to guide the planning group as it defines its own particular roles and responsibilities. In defining roles and responsibilities, the planning group can develop written job descriptions for the co-chairs, paid staff, and committee heads and written descriptions of the group's expectations of individual members.

### 2.3.3 Sharing Leadership

Valuing the group effort also requires members to develop and adopt a philosophy of shared or group leadership, where every member takes responsibility for leadership. The group should avoid passing off total responsibility for leadership to the co-chairs or to any committee or subcommittee heads. When individual members share responsibility equally for leadership and maintenance functions, the group achieves its goals more fully and realizes important benefits (e.g., a more efficient and productive group; increased representation of differing perspectives; increased accountability and cohesiveness).

There are many ways to enlist and ensure the full participation of group members as well as to provide support for the group co-chairs. Some examples include:

- rotating the taking of minutes;
- chairing and/or serving on committees or work groups;
- representing the planning group at professional and community meetings;
- participating in training to enhance member leadership and participation skills.

Members can also broaden their leadership beyond the group to the community by promoting the planning group and its activities to their respective constituencies and helping constituents to understand and provide input to the planning process.

### 2.3.4 Broadening the Impact

The planning group can develop additional roles and responsibilities related to the main goal of developing a community plan for HIV prevention. They include:

- Empowerment. Ensuring the involvement and input of special target groups in the planning process

and in other related community activities. Special target groups can be individuals living with HIV/AIDS, racial/ethnic minorities, women, and others who may not have much experience with community planning. The planning group can work with these groups to increase their capacity for participation in the planning process.

- **Education.** Educating the community at large and serving as spokespersons on HIV prevention and related issues (e.g., sexually transmitted diseases, substance abuse), and building broad-based constituent support for addressing these issues.

- **Communication.** Sharing information on HIV and planning group activities with the community on a regular basis to update them on relevant issues or to inform them about urgent concerns or developing trends in the epidemic.

- **Standard-setting.** Developing standards for prevention messages and methods, including model or instructional interventions, educational materials, and training for prevention workers.

- **Networking.** Establishing linkages among member agencies and individuals that may have never existed, or strengthening those used infrequently. Working relationships can be established to share information and resources on HIV prevention and other related areas.

- **Technical assistance.** Sharing expertise among planning group members including staff training, training of trainers, consultation on specific topics (e.g., interpreting and presenting epidemiologic and other data, team building, program development, evaluation, cultural differences, diversity).

- **Advising.** Working with state and local health departments and other official entities to share information, educate, and provide direction to develop and guide policy on HIV prevention and related concerns.

- **Advocacy.** Becoming advocates for the community, for HIV prevention and related educational activities and for individuals living with HIV/AIDS. This can involve educating health and social service providers, educational institutions, community members, local policymakers, elected officials, and the media.

- **Leadership.** Developing skills and capacities of community groups and individuals to take a leadership role in HIV prevention.

## 2.4 MANAGING THE PROCESS

The planning group, like any new group, will take time to coalesce and develop processes for effective group functioning. The challenge for the co-chairs, and the group as a whole, will be to develop effective and efficient ways for the group to function as a team, make decisions, and resolve problems as it goes about its task of developing an HIV prevention plan for its project area.

### 2.4.1 Teamwork

One important first step in the group process is for members to take specific steps that put the concept of group process into action. Taking action as a

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*"We should remember that this is an ongoing process and trust that we can work together. We need to keep the concepts of partnership and shared responsibility in the forefront."*

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group will build cohesion, allow members to begin to feel a sense of ownership and commitment to the group, and facilitate members to start using a team approach.

Among the type of activities that can build cohesion and allow members to begin to feel a sense of ownership and commitment to the group are:

- Developing a mission statement, planning group goals, and devising a workplan.

- Identifying community-related activities for planning group members. It is a given that the main goal and mission of the planning group will be to develop an HIV prevention plan. However, the group might want to set additional goals or add other tasks to its mission. For example, the group may want to add on a goal of resource amplification (assessing and consolidating resources to avoid duplication of effort and enhance maximization of scarce resources). Or, the group may want to expand the overall mission to include developing networks that will continue to work on HIV prevention and other related issues after the HIV prevention plan is developed.

An effective team can get more work done and better achieve its goals than can its individual mem-



## Building Accountability in the Planning Group

Accountability involves undertaking steps at the beginning of the planning process to guide and monitor the group's progress on a continuous basis until the prevention plan is completed. Attention to accountability at the beginning of the planning process helps the group to set more realistic expectations and to avoid taking on more than individual members can handle.

Group members are accountable to each other in completing their assigned tasks and participating as fair and open members of the group decision-making process. Accountability is not a given, however. In addition, the planning group is also accountable to the community to carry out planning in a rational and effective manner. Following are ways groups can build accountability.

### 10 Ways for the Planning Group to Build Accountability

1. Clearly define the goals and purpose of the group. The goals should define, discipline, and drive the group, its functions, and its philosophy. The goals should energize members to pursue their purpose by the most effective means possible.
2. Carefully select the co-chairs. Selecting the most qualified, experienced co-chairs is key because strong leadership is essential to effective group functioning.
3. Ensure effective goal-setting, strategic planning, and monitoring of progress/activities within the group. Translating a goal into specific tasks and activities is critical to group accountability. This process creates a framework for setting priorities, allocating resources, evaluating progress, and revising plans.
4. Ensure effective feedback and evaluation regarding task accomplishment and process. The group has the responsibility to establish mechanisms for obtaining feedback from members on whether its activities are leading toward accomplishing the goal and on problems that arise to impede the process.
5. Regularly review the performance of the co-chairs, and the heads of committees and subcommittees. One of the most difficult tasks of a group is regularly appraising its performance. It is important for group cohesion and trust, however, to determine how well each group member in a position of power is functioning.
6. Monitor the effective use of all resources available to the group. The group has the responsibility to monitor HIV prevention community planning funds and to share resources with each other.
7. Serve as a court of last resort for complaints. The group should ensure that they have developed structures and processes that guard against arbitrary decision-making and discriminatory behavior, as well as procedures to resolve complaints and conflict.
8. Insist on the transparency of the group. As a publicly-funded entity, the group has the responsibility to be open to public scrutiny and to report on their activities and findings. Conflict of interest policies should be developed to ensure the integrity of both the individual members and the group as a whole.
9. Organize the group to be efficient and effective. The planning group will consist of members who have busy schedules and other commitments. Time will be an issue for all members. In assessing their use of time, the group should consider: Are they hearing not only the good but the bad news (hearing about problems or conflicts) from the co-chairs and committees? Is it making effective use of committees or working groups? Are meetings productive? Are timelines being managed well? Are members able to meet their commitments?
10. Establish a group culture of openness, trust, and candor. In being accountable, members should consistently reaffirm the duty to face, not hide, from problems. The group should strive to create a climate in which problems will be aired, differences expressed, and solutions sought within the context of moving toward achieving the group's goals.

Adapted from Bell, 1993.

bers working alone. However, in order to become a team and work together in an effective manner, members need to be aware of barriers that can impede or disrupt the group process. These barriers include:

- hidden agendas and turf issues;
- internal conflicts;
- unclear roles and responsibilities;
- disagreement or confusion regarding goals/mission;
- weak or nonexistent feedback mechanisms;
- unclear or unfair decision-making procedures;
- excessive member turnover; and
- poor meeting attendance.

## 2.4.2 Code of Conduct

Planning groups will need to develop ground rules for how members will function within the group and within their respective agencies/communities as representatives of the group. Guidelines (formal or informal) can be adopted for appropriate group behavior standards and modified as the need arises. Some issues to consider for members are as follows:

- willingness to act first and foremost as a member of the planning group, and always to act with the best interest of the group;
- ability to put aside individual agendas and separate out the agency's or individual's goals/needs from that of the planning group's;
- willingness to share all information (both positive and negative) with the group in a timely way and a commitment not to withhold information;
- ability to discuss/resolve problems during meetings or committee/subcommittee meetings, not behind closed doors or outside the group;
- ability to be positive about the group, its mission, and its progress;
- ability to exercise discretion to maintain the group's integrity (i.e., no airing of "dirty laundry" in public);
- ability to acknowledge and respect all pertinent variant views on areas/topics; and
- ability to respect each others' differences, knowledge, and work styles.

## 2.4.3 Formal Communications Procedures

It is essential for the planning group to develop a workable internal communication policy and structure to ensure the sharing of information in an open and timely way. When communication is not open, breaks down, or fails, tension, confusion, and distrust can result. If the co-chairs, heads of committees/workgroups, and/or individual members fail to communicate with each other in an open manner, then much of the group's effectiveness and capacity will be impaired. Members can become alienated when they feel information is being withheld; they are not being given accurate and complete information; information is being shared selectively or unequally; or information is not being shared in a timely way.

In developing and implementing an effective communication policy, the group needs to:

- determine how information will be shared among members (e.g., open discussion in planning group meetings, telephone/fax trees, electronic mail, bulletins, meeting minutes);
- share information equally with all members all of the time by not communicating only with those members in one particular reference group and by encouraging members to actively seek out opportunities to engage in dialogue with members they do not know; and
- encourage members to express concerns at an early stage so as to avoid build up of unnecessary tension and misunderstanding;

The planning group also needs to be aware of member differences in communication styles among racial/ethnic minority communities, public health officials, and individuals from specialized disciplines. Members can have different:

- ways of communicating information;
- approaches to decision-making, problem solving, and completing tasks;
- attitudes toward conflict;
- expectations about outcomes (products or conflict resolutions).

Examples of how differences affect communication styles, and ultimately have an impact on the functioning of the group, are illustrated in Table 2-1.

## 2.4.4 Decision-Making

Figuring out how to reach agreement, what to do if agreement can not be reached, and how to move forward during situations of conflict are challenges all groups face. It is important for the planning group not to expect to reach consensus, or even majority agreement, on all issues every time a decision has to be made. The group needs to recognize that they consist of many different players with many different perspectives, and agreement will not always be possible or even desirable. The challenge for members will be to agree to disagree and to then devise strategies for moving on when agreement cannot be reached. This section will focus on developing decision-making procedures for the planning group. Chapter 3 will discuss disagreements, dispute resolution, and conflict of interest.

Groups need to determine a decision-making procedure as early in the process as possible to enable the group to begin to move forward with its HIV prevention community planning effort. There are many models for decision-making. Two models are discussed here: 1) decision-making by consensus, and 2) decision-making by group vote.

**2.4.4.1 Decision-Making by Consensus.** Under the consensus style of decision-making, members arrive at a shared decision. This requires all parties involved in the process to support the final decision. This does not necessarily mean, however, that all parties have compromised (given something up) in order to sup-

*"The community planning process isn't perfect. You risk that there will be individuals who are disruptive, who don't want the process to work. But the group is self-regulating. The group will push everybody to move on. It's peer regulated. This is a benefit of the community planning process. It's less adversarial and based more on partnership."*

port the final decision. Consensus decision-making requires that all parties continue to work together and discuss the issue until they incorporate all points of view into the final decision (thereby making it a shared decision). This can be difficult to accomplish and can

**Table 2-1:**  
**Differences in Communication**

1. **Presentation and Terminology.** How people present information and use terminology differs from group to group. Some groups communicate in academic or scientific styles and use technical terms, while others speak less technically and use everyday language. In addition, different ethnic groups can employ figures of speech that are hard to translate into mainstream English, and professionals can use technical "jargon" that can be unfamiliar to laypersons.
2. **Organization.** How individuals organize information can vary. Some people are very methodical, logical, and orderly in their organization of information, and other individuals are less so. While some may perceive the less organized communicator as chaotic, confusing, and not very credible, the precision-oriented communicator may appear boring, manipulative, and controlling to others.
3. **Specificity.** Some individuals prefer to start conveying information with specifics and then expand to the broader topic or main point. Other people like to start with the broader information and then provide the details.
4. **Assertiveness.** People have different comfort levels with assertiveness. This comfort level may vary with an individual's knowledge base about particular issues. An individual may feel uncomfortable communicating information on a topic they do not know a lot about but be able to lead a training for the group on a topic they know well.

end up being very time consuming. Some groups reserve a voting process as a backup method if they get stuck and cannot reach consensus.

Consensus means that:

- all members contribute to the discussion;
- all members are able to state the issue/problem in their own words;
- everyone is given the opportunity and time to express their opinion about the issue/problem;
- members who continue to disagree agree to support the group decision on a trial basis; and
- all members agree to take responsibility for the implementation of a decision.

Consensus does not mean that:

- a vote is unanimous;
- the result is every member's first choice;
- all members agree; and
- conflict or resistance will be overcome immediately.

**2.4.4.2 Decision-Making by Group Vote.** In this model, groups make decisions by discussing issues in an open forum and then voting and/or polling individual members. If the majority is in favor, the vote is accepted as a decision. Decisions are made based on the broad agreement of the group and it is expected that not all members will agree with the decision. Because of this, individuals do not have to compromise their position or come to agreement as a group. Groups need to leave ample time for discussion of issues and expect that some members will still register complaints about having insufficient discussion time.

**2.4.4.3 Voting Procedures.** In developing a voting procedure, the planning group needs to consider the following:

- Mechanics of voting. Will votes be by voice, hand, or written ballot? Who will be responsible for taking and recording votes? How will they be documented?
- Requirements for voting. Does the entire group need to be present to vote and is unanimity required (i.e., consensus)? If unanimity is not required, will quorums or percentages be used and, if so, what will those numbers be (this often varies based on group size)? If the entire group does need to be present for voting, will there be any provisions for absentee voting or voting by proxy? Will committees or subcommittees be given authority to vote on some issues and not bring them before the full planning group?
- Procedures for stalemates. Will the group allow the planning process or task/issue in question to go forward if consensus cannot be reached or a majority vote obtained? What procedures will be developed to resolve disputes in order to keep the planning process on track?

## 2.4.5 Operating Procedures

Operating procedures exist to help the planning process run smoothly and stay on track. They exist on several levels. The development of a workplan is

key to staying on schedule. The role of co-chairs in facilitation and coordination is also critical in keeping the planning process on schedule and ensuring open dialogue among members. Officers of the group, such as a secretary or recorder, can facilitate information flow or perform other specialized tasks. Committees can be established to carry out specialized or focused activities that would slow down the group process if conducted by the full planning group. Finally, formal procedures exist in conducting efficient and productive meetings.

**2.4.5.1 Objectives and Workplan.** Planning groups will need to develop objectives for group goals, activities, or tasks to implement the objectives, and a workplan with milestones to measure progress. The objectives need to be realistic, clear, measurable, and time limited, and reflect what needs to be done to develop the HIV prevention plan. The workplan will list the specific activities or tasks to accomplish the objectives and assign responsibility among members for completion. Milestones should be noted on the workplan. Groups might want to establish only a few key milestones to avoid taking on more than is manageable.

The co-chairs can guide this process and work with the group to develop objectives and set milestones. The task of developing a workplan can be assigned to a committee or work group. Co-chairs can also assign working on objectives and milestones to committees or work groups, but may want to first get broad-based agreement from the whole group as to basic activities and direction.

**2.4.5.2 Co-Chairs.** HIV/Planning groups are co-chaired, with one individual selected by the grantee and one to be designated by the planning group. Their job is to direct and guide the process without dominating it. Key responsibilities of co-chairs are as follows:

- Moderate and facilitate meetings. This involves the ability to balance input and discussion among members, seeking out those members who are not participating and moderating input from more vocal participants.
- Recognize important issues. Co-chairs can guide members in identifying the most critical concerns in the needs assessment process. They need to be able to condense and organize input from members into a rational and understandable framework.

- Motivate participation. Conveying enthusiasm, motivating participation, and keeping attention to the goal at hand is a critical role because the process will inevitably bog down over difficult issues and disagreement. When members do not attend meetings regularly or miss important sessions, a co-chair should make contact to ensure that they are included in the process as it unfolds.
- Structure group and individual interactions. People and organizations will bring diverse perspectives and agendas to the group. Differing perspectives can cause disagreement and conflict. Co-chairs can work to direct discussions so that they are more productive and less confrontational.
- Sense when agreement begins to emerge. Co-chairs need to identify and highlight trends in group thinking and move the group forward. This sense of pro-

### Table 2-2: Evolution of a Group

Following are three general stages that groups experience as they progress from start-up to maturity. Co-chairs should keep these general stages in mind in monitoring the group's ability to stay on course.

**Stage 1. Evolution.** Problem-setting stage where issues are specified and those with legitimate stakes in issues are identified. This includes: full range of stakeholders are identified and involved; stakeholders agree about legitimacy of each other's participation; stakeholders expect that benefits of collaboration will outweigh costs; prevailing norms support collaboration, or incentives are available to induce participation; stakeholders recognize their interdependence; conveyors possess legitimate authority and ability to "appreciate" the potential for mutual exchange.

**Stage 2. Direction Setting.** This involves identifying a shared vision and values, and setting goals (co-incidence of values among collaborators, joint participation in data collection, dispersion rather than centralization of power among stakeholders).

**Stage 3. Structuring.** The creation of formal and ongoing structures for implementation occurs (members perceive need for continued interdependence, can negotiate about how to take action, distribute power, monitor, and manage changes in their environment).

CDC, 1993

cess is important in keeping the effort on track over time. Co-chairs need to be aware of the growth and evolution that often occurs among groups as they develop and take action if the group fails to progress to the next appropriate stage of development. Table 2-2 presents an outline of this evolutionary process.

Co-chairs also need to work on balancing their roles as leaders and as mobilizers of the group psyche. A co-chair who takes too much initiative or over-controls discussion and direction of the group will risk dominating the process. This will alienate members and hinder the participatory process. On the other hand, a co-chair who takes too little initiative risks losing direction, which may lead to no action or lengthy delays in the decision making process.

A critical decision for grantees is how to structure roles and responsibilities of the two co-chairs as they carry out their jobs of managing the group process. What responsibilities will they share? How will they complement each other? Several options are feasible.

- Shared responsibilities. This can include facilitation of meetings in which the role of meeting chair rotates for each meeting, joint oversight of staff and committee activities, and shared responsibility to coordinate the planning effort.
- Segmented responsibilities. Roles and activities can be organized along lines of broad task areas. For example, one co-chair could facilitate meetings while one manages and oversees subcommittee assignments and the day-to-day needs assessment process. Some rotation in these assignments could also occur over time.

Cautions are in order in discussing co-chair responsibilities. First, groups should avoid having co-chairs share facilitation roles for the same meeting. Confusion is likely to occur given that the co-chairs are very likely to perceive group dynamics in a particular meeting somewhat differently. Even slight differences in interpretation and guidance may appear disjointed and contradictory and end up being harmful to the group process.

A second concern is that the grantee-designated co-chair not become solely identified as the health department co-chair. Although this individual will likely serve as the primary liaison with the grantee, the other co-chair also needs to be brought into this process. Otherwise, the other co-chair (the non-grantee designated co-chair) might become, by default, the key advocate for community members. The outcome

might be creation of division of members along lines of loyalties to one co-chair or the other.

**2.4.5.3 Officers.** Some group activities are best accomplished by an individual who will devote specific and ongoing attention to assignments. These are assignments that cannot be carried out by a group or committee (e.g., monitoring the budget, taking meeting notes, notifying members of upcoming meetings). Such positions are usually designated as officers of the group. When established, they should be organized around written job descriptions and agreements with the officeholder. This will make the scope of responsibilities clear to both the officeholder and the group and provides a level of accountability for responsibilities. Common officer positions include the following:

- **Secretary.** Tasks can include meeting note-taking, recording major decisions and votes, and notifying members of upcoming meetings. (These tasks may also be carried out by professional staff.)
- **Parliamentarian.** Tasks include keeping the group on track in terms of their agreed upon rules of order. This individual may not be needed if the rules of order are fairly informal; the co-chairs can serve this function. However, structured meetings will require an arbitrator of the rules.
- **Treasurer.** Tasks include monitoring of expenditures and approving and overseeing outlays of funds, as approved by the group or co-chairs.
- **Media spokesperson.** Groups might consider designating a single individual to serve as the liaison for all press inquiries. This helps avoid providing the media with conflicting information. Also, the media spokesperson can be trained and may have particular skills in handling public inquiries.

**2.4.5.4 Committees and Work Groups.** While the full planning group stays focused on the overall planning effort, specific assignments and issues can be addressed by committees or work groups. Committees can be either standing committees (i.e., ongoing roles, such as a steering committee, epidemiology committee) or have limited lifespans (e.g., nominating committee).

A steering committee, or executive committee (if created), enjoys a special status. It acts as the focal point for discussion of major decisions when such issues are not effectively addressed by the larger planning group.

In organizing committees, the following should be considered:

- designate chairs of committees with experience in facilitation;
- seek diversity in the individuals designated as committee chairs;
- train committee chairs, if needed, in group facilitation processes;
- require committees to define their work, needed resources, time frames for accomplishing activities, and individual members who are responsible for specific tasks;
- have committees report to the larger planning group on a regular basis so that their efforts and progress can be factored into the group process; and
- resist forming too many committees and remember that every committee will have to be managed somehow and its activities will, at some point have, to be merged with the larger planning groups.

**2.4.5.5 Running Meetings.** Regardless of the group decision-making process adopted by the group, it is essential to adhere to certain rules of procedure in conducting meetings. Otherwise, meetings will become inefficient and attendance will drop. Common meeting rules include:

- **Schedule meetings at a standard time.** Members should agree on the most convenient time and location for meetings and stick to that schedule.
- **Prepare agendas.** An agenda will help keep the meeting on schedule. Also, members will have a better picture of the structure and key points to cover and may fashion their comments and input accordingly. When possible, provide agendas and minutes of past meetings to attendees in advance of meetings.
- **Review assignments.** At the end of the meeting, review assignments and deadlines. This is an effective way to hold members and agencies responsible for completing their tasks.
- **Designate meeting chair role.** In addition to moderating the meeting, chairs should be charged with monitoring progress of tasks, keeping the group on schedule, and motivating and encouraging regular attendance by members. The latter is important and can involve maintaining regular contact with members



through mailings, telephone calls, and special efforts to confirm attendance at meetings (e.g., request members to complete a meeting attendance confirmation check sheet in advance of the next session).

- Assess the process. How well the group is functioning, effectiveness of its decision-making process, productivity of committees and work groups, and how members are feeling about their involvement in the group process are all areas that need to be reviewed periodically. This can be accomplished with written feedback and/or open discussions that are led by a trained facilitator. Table 2-3 contains a sample self-assessment form for group members. (Refer to Chapter 8, *Evaluating the Community Planning Process*, for more information on evaluating the group's effort.)

## 2.5 KEEPING ON TRACK

All groups reach a stage or go through phases where they are in danger of getting stuck and/or losing momentum. What follows are examples of how groups can get stuck and suggestions for how to regain momentum.

- Loss of direction or focus. If the group gets distracted with other issues or activities that are not related to its goal, the group can lose its focus.

Suggestions for regaining focus include: review the mission statement and goals; revisit the objectives and workplan; highlight milestones and accomplishments to reinforce the group's goals.

- Loss of leadership or leadership struggles. Groups can depend too strongly on a particular leader (co-leaders, heads of committees, officers)—even when group leadership is shared—and fail to develop new leaders (when officers want to rotate off or new committees or work groups are created). Groups can also develop factions or cliques and create situations in which several potential leaders are competing to try and gain influence in the group. Situations like these can leave the group without clear leadership and challenge the principle of shared leadership.

Suggestions for clarifying and reinforcing shared leadership include: change or add to roles of members to reinforce shared leadership; encourage committees to be more active; encourage broad-based agreement and consensus in decision-making, when appropriate; develop "role" descriptions for the various members that

emphasizes shared leadership; hold a special meeting to discuss differing viewpoints when they start to split the group into sides; and use an outside consultant to facilitate the meeting.

- Founder-member syndrome. Sometimes founding members of a group gain significant power and status by virtue of being with the group from its inception. They may find it difficult to include new members in meaningful roles. It is important to note that not all founding members of a group exhibit the founder-member syndrome. Many continue to be great resources, adept leaders, and skillful delegators.

Suggestions for dealing with this syndrome include: enlist other founding members in conducting orientation and providing guidance to new members, e.g., develop a new member "buddy" system; assign new responsibilities that use the founding members' strengths.

- Unequal involvement and recognition of members. Involvement and recognition seem to go hand-in-hand. Members who get involved tend to be better informed and gain more power. Uninvolved members may lose interest and eventually leave the group.

Suggestions: create opportunities for every member to be actively and significantly involved in the process; rotate leadership positions e.g., heads of committees, work groups; empower individuals to participate through training; provide orientation to all new members; recognize member contributions and accomplishments as frequently as possible.

- Poor planning efforts. Groups can run into problems if they do not plan well. Objectives may be too ambitious and timeframes may not be long enough.

Suggestions: revisit the objectives and workplan; make adjustments in milestones (if possible); recruit more members to the group; develop additional work groups; enlist the support of volunteers or interns.

- Negative publicity. Adverse publicity can threaten the credibility of the group in the eyes of the community at large, the group's target population(s), and local leaders in business, government, and media.

Suggestions: appoint one member as a spokesperson, preferably someone who is experienced in dealing with the media; launch a public relations campaign to correct the inaccurate criticism; develop a crisis commu-

**Table 2-3:**  
**Sample Self-Assessment Form for Use by the Planning Group**

The purpose of this self-assessment is to provide an opportunity for planning group members to provide input to the process and the policies that govern meetings. The results will be summarized by the co-chairs [or assessment committee] and distributed to all members. Your input is important to the successful and efficient functioning of the planning group. Thanks!

Directions: Please indicate your agreement or disagreement with the statements below by circling the number on the scale that best represents your experience on the planning group. We prefer that your responses be anonymous, so please do not include your name.

	Completely Agree			Completely Disagree		
1. The atmosphere is friendly, cooperative, and pleasant.	1	2	3	4	5	
2. The purpose of each task or agenda item is defined and kept in mind.	1	2	3	4	5	
3. Everyone participates in discussions, not just a few.	1	2	3	4	5	
4. There is no fighting for status.	1	2	3	4	5	
5. There is no fighting for hidden agendas.	1	2	3	4	5	
6. The group uses the resources of all, not just a few.	1	2	3	4	5	
7. Members stay with the task.	1	2	3	4	5	
8. The group adjusts to changing needs and situations.	1	2	3	4	5	
9. Members feel safe in speaking out.	1	2	3	4	5	
10. Meetings have free discussion.	1	2	3	4	5	
11. Interest is generally high.	1	2	3	4	5	
12. Meetings run smoothly, without interruptions or blocking.	1	2	3	4	5	
13. Meetings start and stop on time.	1	2	3	4	5	
14. Members seem well-informed and up-to-date and understand what is going on at all times.	1	2	3	4	5	
15. Technical terms and acronyms are clearly defined and understood by all.	1	2	3	4	5	
16. Routine matters are handled quickly.	1	2	3	4	5	
17. Committee and/or work group reports are routinely made to the entire group.	1	2	3	4	5	
18. The group advises and makes recommendations to the state and/or local health department.	1	2	3	4	5	
19. The roles of professional staff are clearly defined and followed.	1	2	3	4	5	



20. The roles of the grantee and planning group are clearly defined and followed.	1	2	3	4	5
21. Materials for meetings are prepared adequately and in advance of meetings (agendas, minutes, study documents).	1	2	3	4	5
22. Minutes accurately reflect the proceedings of the meeting.	1	2	3	4	5
23. Members have a good record of attendance at meetings.	1	2	3	4	5
24. I am usually clear about my role as a planning group member.	1	2	3	4	5
25. My assignments are manageable and not overburdening.	1	2	3	4	5
26. Meeting times work well with my schedule.	1	2	3	4	5
27. Notification of meetings is timely.	1	2	3	4	5
28. Location of meetings is convenient.	1	2	3	4	5

29. Do you feel that your expertise or talents are being used well? ☐ Yes ☐ No

If no, how could they be used more effectively?

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30. What changes would make the planning group more effective?

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31. What changes would make serving on the planning group more enjoyable?

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32. Other comments/suggestions:

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Adapted from Minnesota Department of Health, 1990.

nications plan and a crisis response team (provide training as needed).

- Failure of planned activities. Despite the best efforts, plans for some activities may fail. The result may be low morale and frustration among group members.

Suggestions: hold a debriefing session for all members involved in the activity; study the causes of the failure to learn for future activities; recognize any possible positive results; get feedback from outside, objective sources.

- Burn-out or unrealistic demands on members. Task-oriented groups can demand a lot of time from members, especially the co-chairs. If responsibilities are not shared equally among all members, some members may take on too much and experience burn-out.

Suggestions: monitor the process to determine if activities need to be speeded up or slowed down; rotate officers and committee and work group heads; complete one task or step before even considering another; segment out tasks to committees or workgroups to work on simultaneously; sponsor member events that are just for fun; offer seminars on burn-out prevention and stress reduction.

- Absenteeism and turnover. The group needs to expect that not all members will participate fully and attend all meetings. Likewise, the group needs to expect that there will be turnover among members and staff.

Suggestions: revisit decision-making procedures and use proxies when members cannot attend meetings; create a waiting list for membership; establish backups for individual members who have HIV/AIDS, who may not be able to attend all meetings due to

unanticipated illness.

- Bureaucratic structure. Any group can become too bureaucratic, inflexible, and difficult to manage. Bureaucracies have a tendency to take on a life of their own and lose touch with the needs of its members and the community.

Suggestions: reduce the layers between the top leaders and the members; simplify policies and procedures; hold sessions on managing change and look at new ways to involve members; delineate clearly in the bylaws the frequency of rotation of officers, committees and/or workgroups; how membership will be handled if there are consecutive unexcused absences; how unexcused absences will be defined.

- Turf battles and competition. Turf battles can occur when there is actual or perceived competition among members' agencies for funding, clients, volunteers, or visibility. Differing value systems or professional philosophies, personality conflicts among leaders, and past negative experiences among organizations can set up competitive situations. While competition is natural, and even expected in a group, it can lead to turf battles that can be extremely disruptive to the group.

Suggestions: arrange opportunities for member agencies to talk about their differences (sometimes conflict can be caused by misunderstandings); facilitate a session to mediate differences or arrange a compromise; look for areas of agreement and opportunities for cooperation; help the group to focus on the common ground within the group and on the group's goals (not all turf battles or competitive issues need to be resolved in the group); bring in a professional facilitator or mediator to hold session to build trust and reduce conflict. (National Association of Social Workers, 1993)

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# Notes From the Field:

## Valuing and Managing the Community Planning Process

### OVERVIEW

All state AIDS directors attested to the value of the community planning process. Many thought an important role for the state health department was to ensure that state and local health department staff and others perceived and understood the value and benefits of this process. They considered it essential to have the support of all partners in this process from the state health commissioners to the various community constituencies represented "at the table."

Managing the process carefully and correctly was also viewed as a key element to its success. As one state AIDS director commented, "Community planning deserves to be done right." Based on previous experiences in managing HIV prevention planning activities in their states and on current efforts "to plan for community planning," respondents offered many ideas and recommendations on how to ensure an effective and efficient community planning process.

### SETTING EXPECTATIONS

Be realistic. The importance of both the state health department and the community being realistic about what can be accomplished was stressed. "Helping to manage these expectations" was described as a state health department role. One respondent indicated, "There needs to be a balance between involving and overinvolving the community." Another stated his understanding that "CDC wants a good faith effort to start the planning process in year one." He indicated that for any state, community planning can be a full-time enterprise. Planning takes enormous effort and time to do it right. A key ques-

tion for most states is "what is reasonable and realistic to do in the first year."

*Adhere to the principles set forth in the CDC guidance.* In approaching HIV prevention community planning, all the states seem to be committed to developing the process in accordance with the principles set forth in the CDC *Supplemental Guidance*.

*Obtain consensus on principles.* In addition, one state AIDS director described how the state health department jointly with the local health departments came to consensus on seven planning principles to guide the community planning process in his state. The consensus process by which they came to agreement was as important as the principles that were drafted. This is discussed in more detail in the section below on "Building Trust."

*Take existing HIV prevention plans as a starting point.* A key reminder from one state was the importance of remembering "You are not starting in a vacuum. Remember that some planning activities have already occurred. Build on this experience, both good and bad." Several states intend to have the newly constituted community planning groups review and as-

### Prevention Planning Profile

In Minnesota, members of the community have been involved since 1986 in the state's overall plan for HIV prevention, development of RFP's, and selection of grant recipients. Both a standing task force on services and a new task force on community prevention planning will build their efforts on existing plans that were developed with extensive community participation.

sess current HIV prevention plans that are in place and make recommendations for change. As one state AIDS director indicated, these previous plans may be "chock full of good ideas" that need to be evaluated by these groups for their relevancy for the future.

**Integrate new plans with existing plans.** More than one state indicated that being realistic about this process is not just viewing planning as a long-term effort, but also recognizing that there are other planning efforts ongoing. A key consideration for state health departments should be the integration of the new HIV prevention community planning effort with other federal, state, and local health plans and funding allocation efforts. This is not just an issue of coordinating strategic plans and allocating resources. The planning process will yield important information that may have an impact on other planning efforts.

**Think through the process.** One state AIDS director advised that the states should "think through the process step by step....Have an idea of how it might unfold. Ask where you are going to be in the process six months, 12 months, 18 months from now. Try to anticipate the questions up front." Anticipating the questions and potential problems in advance should enable the state to identify technical assistance and other forms of support to ensure the effectiveness and efficiency of the community planning process.

**View planning as a long-term effort.** A lesson learned from one state's past experience is that "This is a long-term process of readjustment, redirection, and planning." This state is looking at community planning over five years not one year. The state AIDS director

### Prevention Planning Profile

Michigan has in place a five-year plan for prevention and care developed with public input. A statewide conference and public hearing solicited comments from a large number of community participants diverse in terms of geography, gender, age, race, ethnicity, sexual orientation, and risk behavior. After this public hearing, a working group of 30 people involved in the conference organized the public testimony according to needs and issues and set priorities among them. This became the basis for the state's five-year plan, which is currently used to guide and make decisions. Michigan will submit this plan to the community planning groups and ask them to validate it, asking the questions, "Is the plan still valid? Is it still relevant? Should we be doing something different?"

reminds other states that although the community planning process needs to start in year one, "we need to build on it in years two through five."

**Orient participants properly.** According to several state AIDS directors, one of the key considerations for starting the planning process correctly is proper orientation. If not done adequately, orientation can pose a serious barrier to the planning process by not ensuring parity of information and skills among participants. But as one respondent cautioned, "Be realistic about what you hope to accomplish."

Another respondent stated, "It is important to bring everyone to the same playing field." Several recommendations were made with respect to orienting not only community participants but also state and local health department staff involved with the community planning process.

**Assess knowledge and skills of participants; design targeted orientation and training.** One state recommended that in designing any orientation or training effort it is imperative to remember that "diverse groups have varying levels of expertise." It may be unrealistic to expect and provide uniform training for all group members. Specialized targeted training that is customized to different levels of expertise and knowledge of the subpopulation groups within the membership is needed. Otherwise, what can realistically be accomplished in a general orientation to a topic will be a brief overview of the subject and identification of areas for future training.

### CLARIFYING ROLES AND RESPONSIBILITIES

Part of ensuring realistic expectations for the community planning process is defining clearly the roles and responsibilities of those who will participate in the process. As one respondent stated, "Participants need to know why they are on the committee. Some of them may serve more than one role. This should be defined in the selection process. How people present themselves is important. They need to be clear about whom they represent."

### BUILDING GROUP ACCOUNTABILITY

Establish ground rules. Some of the states stressed the importance of clarifying and establishing ground rules early on in the community planning process. They advised it may be helpful to have certain policies, procedures, and standards

available in written draft form for the planning group's consideration.

In one state involved with Ryan White consortia, certain standards with respect to resource allocations and selection of CBO contractors were not set up in advance of decision-making. Problems that occurred because of this omission resulted in later development and imposition of standards on groups that were already up and running. This created a great deal of conflict.

Several states have convened advisory or working committees to assist in the process of constituting the community planning groups. Some of these committees have been charged with developing the ground rules according to which the planning groups will be structured and operate, including by-laws and standards that will establish operating protocols for nomination and selection, membership criteria, use of alternates, group attendance, voting, conflict of interest, selection of group leaders, etc.

*Arrive at decisions by consensus.* Some of the states indicated the importance of the planning groups agreeing from the start on how they will come to consensus and determining how they are going to function if conflict arises. One state stressed the value of having the group commit to developing a plan and be ready to compromise. Groups should acknowledge and "know up front that compromise is necessary."

The prevailing view among the state AIDS directors seemed to be that the planning groups should arrive at decisions by consensus rather than by voting. One state indicated that in its past experience if a working group could not arrive at a consensus on an issue, it might go to a vote and the state health department would at times be involved in helping make the decision.

Another state's view was that although the state health department would encourage a consensus approach based on open and full discussion, if its local health departments and planning groups preferred to operate by Robert's Rules of Orders and formal votes, the state would support their decision to manage the decision-making process in that manner.

## DEVELOPING GROUP LEADERSHIP

**E**lect talented and effective co-chairs. All the states indicated that in compliance with the CDC *Guidance*, community planning groups will have co-chairs, one from the state health department, the other elected by the group from its membership. One state stressed how important it is to have

talented and effective leadership of these groups. A weak or ineffective chair can cause a lot of problems for a group.

*Define the role of the state health department co-chair.* In one state that had a very positive experience with Title II Ryan White Planning Consortia, the state health department official served as co-chair of the statewide planning group. In this capacity, he served as part facilitator, part convener, part advisor and was a voting member of the group for its first three years. The state health department role was to convene the working group and help it get through the process of planning. By year four, the decision was made to remove the state health department from the voting process to minimize potential conflict in decision-making.

This state health department recommends that the role of its representative as co-chair in the new community planning should be similar. The state health department co-chair should help convene, facilitate, advise but have no voting rights in the group. The community should retain ownership of this process.

*Ensure that all participants feel free to speak.* Several respondents mentioned the importance of ensuring that all members of the group have input and feel valued for their contributions. All must have a "voice at the table" in order to participate fully in the decision-making process by the group. This not only relates to the issue of parity discussed earlier, but also to fostering a group culture of leadership in which all members of the group feel accountable, responsible, and capable to move the planning process forward.

## KEEPING THE PROCESS GOING

**P**rovide adequate training and technical assistance throughout the planning process.

All states were anticipating the need for training and technical assistance on a wide range of subjects not only for members of the HIV prevention community planning committees, but also for key state and local health department staff involved in this process. Respondents identified many topics that should be introduced as part of orientation efforts and serve as the focus of future training and technical assistance.

In some states, the state health department has had experience in providing training and technical assistance in these areas and its staff will design and provide some of the orientation. In other states, outside



## Prevention Planning Profile

California, as part of its Title II planning process, convened a group of technical advisers, including community development experts, HIV specialists, epidemiologists, university researchers, federal public health service staff, and state experts on TB, STDs, and maternal and child health issues. These technical advisers provide knowledge and expertise to the Title II statewide working group. They are required to attend all working group meetings and to sit at the table with the voting members. Their purpose is to help the working group make decisions by providing experience, expertise, training, and technical assistance. Eighty percent of these advisers will also serve the new statewide preven-

experts and consultants would supplement and assist state health department staff in planning and delivering orientation, other training events, and follow-up technical assistance.

A concern voiced by one state was that "People will be anxious to start planning but first you have to get everyone up to speed. There's not enough time though to do this within the timetable we've been given."

## PROVIDE FACILITATION

**U**se trained group facilitators. Based on their positive experiences in using third parties to facilitate groups, several states recommended strongly the use of trained group facilitators outside the state health department. As one state indicated, "When you bring people together for the first time they come in with their own agendas and often a distrust for the government. We needed someone outside the government to be a lightning rod." Another state is using an outside facilitator who has a background in group dynamics to help its nominating committee with the process.

## Prevention Planning Profile

With its Title II planning groups, California used a team of facilitators right from the beginning. Trained facilitators from the community were recruited by the California Association of AIDS Agencies. Involving the community in facilitating the planning group helped build trust and parity in voices around the table. The state will also use facilitators throughout the community prevention planning process. The facilitation teams that are hired should reflect the community planning groups, which in turn represent the larger community.

South Carolina has a network of 150 group facilitators. The health department anticipates tapping into this existing network to help develop focus groups.

## BUILDING TRUST

**M**ost respondents stressed the importance of building and maintaining trust not only between the health departments and the community, but also between the state health department and local health departments. This element of trust is viewed as key to the success of the community planning process.

The state AIDS directors indicated that currently their state health departments have very good relations with their counterparts on the local level and with the community at large. Historically this has not always been the case. These state health departments have worked very hard to establish good collaborative and cooperative relations with their local health departments, their CBO contractors, and other community providers and clients with whom they interact around HIV care and prevention issues.

*Provide community planning groups with purpose and authority.* Most state health departments have solicited community participation or input with respect to HIV prevention. Participation that has resulted in meaningful dialogue about issues, recommendations, or decisions has also led to the establishment of trust between the community and the state health department. On the other hand, advisory groups or committees that were not truly representative of the community, not given a clear goal, and formed without a sense of purpose or authority could erode good relations between community groups and the health department.

As one respondent stated, "How the group is generated has a lot to do with its success or failure. A group with purpose and authority will have more energy and be more useful." States thought that the community planning process will be much more likely to succeed since planning groups have a mission to accomplish and the authority and support to complete it.



*Support the decisions of the planning group.* One state AIDS director indicated the importance of accepting and supporting the decisions arrived at through the community planning process. The state health department must be prepared to bring the recommendations of the planning groups to the highest levels of government and to stand by those decisions. Other respondents indicated the importance of using and applying those recommendations to the development and implementation of policies, programs, and interventions for HIV prevention.

### Prevention Planning Profile

Three years ago Massachusetts set up an ad hoc advisory groups to assess HIV counseling and testing utilization and to determine use of these services by people of color. A year-long task force consisting of groups that served the community and people of color was established. It was composed of leaders of communities of color who were asked to think through counseling and testing policies and their implications for minority access. The task force helped to shape an RFP that resulted in shifting of state funds to increase counseling and testing services for people of color.

### Lessons Learned on Building Trust with Community Groups

- Solicit community participation and feedback in a thoughtful way.
- Listen respectfully to recommendations made and act on them.
- Keep communications open.
- Provide a clear goal for community participants.
- Trust community participants to do a good job.
- Give community participants the authority and support to do their jobs right.

- Create as many opportunities for collaboration as possible.
- Assess where you are in terms of your relationship with the community before proceeding.
- Work proactively to improve levels of trust.

*Involve local health departments early on.* In some states, the local health departments operate independently from the state health department. They may look to the state for funding but not necessarily for guidance or regulation. In many states, local health departments may ultimately be responsible to their communities for the prevention and control of disease. The state health department role may be to provide technical assistance and other forms of support upon request.

### Prevention Planning Profile

Since 1985, planning in Oregon has shifted from the state to the local level. The emphasis in HIV prevention community planning will be on an open and inclusive process coordinated on the local health department level. The role of the state health department will involve monitoring, oversight, data collection, training, and technical assistance to the local health departments to support them in coordinating local planning. Oregon will develop 34 local HIV prevention plans corresponding to 34 local health departments serving 36 counties. Oregon is convinced that the way to proceed with HIV prevention community planning is to adhere to local planning with limited state involvement.

One state indicated "We try to maintain a very collegial relationship with the local health departments." With respect to HIV prevention community planning, another respondent stated, "It is imperative that our local health departments be involved because of their power and responsibility to the local communities."

### Prevention Planning Profile

South Carolina's collaborative efforts during the past five years have resulted in increased trust and good relations between the state health department and the community. This foundation of trust will help the development of the community planning process. These efforts have included state funding and support for many CBOs; soliciting feedback from health care workers and community providers; co-sponsoring conferences for a variety of community constituencies; and collaborating with many community agencies to plan a statewide conference called, "Building the Bridge."

## Prevention Planning Profile

In developing its "plan to plan," Michigan invited its local health departments and community based organizations, through a series of five meetings, to come up with principles about how community planning should proceed in the state. Although reaching consensus on seven principles was difficult, involving local health departments in this task helped them feel some ownership over the planning process. They also agreed to eight regional planning areas that respected the geographic boundaries of the state's 83 counties and 50 local health departments. The state tried to honor the integrity of existing public health jurisdictions.

The seven principles drafted by Michigan's state health department were that the structural and functional configuration of prevention planning in Michigan:

- must assure compliance with the intent of the CDC supplemental guidance and requirements outlined within, especially with respect to ensuring that the planning process involves expected community input and participation with an emphasis on proactive recruitment of representatives from relevant affected groups;
- should, to the extent possible, maintain the geographic integrity of existing local public health jurisdictions;
- should, to the extent possible, be homogeneous with respect to HIV/AIDS epidemiology, health status indicators and general socioeconomic profiles;
- should be such that planning bodies can maintain active communication and participation in the activities of other planning bodies, particularly those in bordering regions;
- must be administratively manageable and resource effective;
- will allow for adjustments based on the first year's experience. Planning is to be viewed as long-term in nature.

## BROADENING THE IMPACT AND BENEFITS

**S**hare the power. One state health official articulated well the potential positive impact and benefits that will result from HIV prevention community planning. For state and local health departments, which may have become "entrenched in the status quo" and whose programs and organizations may have become "settled" and "institutionalized," community planning provides an opportunity for staff "to rekindle the original reason that we're here: to fight the epidemic and to care for affected and infected people. It's a unique epidemic, requiring unique solutions." This state AIDS director also stated, "There's a feeling that if you share power you lose power. Just the opposite is true. When you share power, you gain power. By involving all stakeholders in the debate and decision-making, everyone is empowered by being involved in the community process."

*Develop a partnership model.* According to this respondent, to realize the benefits of a community planning process that is predicated on a partnership rather than on an adversarial model, state health staff need to be able to step out of their traditional role as government officials who exert control and power. They need to "accept the values that communities value" and the "value of community advice." There is a risk involved in letting the process go because the process is not perfect. But groups become self-regulating and will move themselves forward.

## How to Ensure an Effective Community Planning Process

The following list summarizes the collective wisdom of the state AIDS directors on how state and local health departments can support the HIV prevention community planning process to ensure its effectiveness and to achieve its potential benefits and intended impact.

- Make sure that the right people are participating, planning, and executing.
- Ensure an open nomination process.
- Do your homework.
- Introduce the process properly. Orientation is very important.
- Elect talented, effective co-chairs for the planning groups.
- Set up a planning structure to minimize conflict.
- Establish community ownership of the process early on.
- Clearly define roles, responsibilities, and authority.
- Draft operating principles, standards, and policies in advance.
- Understand the size of the commitment participants must make.
- Ensure that the planning groups have real authority and purpose.
- Let go. Trust that the people in the community will do a good job.
- Give the community credit if something goes well. Be willing to accept the blame for things that go wrong.
- Be flexible.
- Keep cool.
- Cultivate good listening skills.
- Have a positive attitude and a willingness to learn from new experiences.
- Encourage a consensus process in meetings.
- Agree on how to come to consensus and how to function if conflict arises.
- Develop a protocol for addressing and resolving conflict and conflict of interest.
- Allow local health departments and community groups autonomy in determining how the community planning process will take place.
- Have faith in the process.
- Commit to developing a plan and be ready to compromise.
- Support the community planning group's decisions and recommendations.
- Follow through on your commitment to follow through.
- Encourage open, facilitated discussions in which all participants feel free to speak up.
- Be willing to take risks.
- Build on previous planning successes.
- View this not only as a tremendous challenge but also as a tremendous opportunity to improve HIV prevention programs.



# Handouts

H. Roberts

## Building Accountability in the Planning Group

Accountability involves undertaking steps at the beginning of the planning process to guide and monitor the group's progress on a continuous basis until the prevention plan is completed. Attention to accountability at the beginning of the planning process helps the group to set more realistic expectations and to avoid taking on more than individual members can handle.

Group members are accountable to each other in completing their assigned tasks and participating as fair and open members of the group decision-making process. Accountability is not a given, however. In addition, the planning group is also accountable to the community to carry out planning in a rational and effective manner. Following are ways groups can build accountability.

### 10 Ways for the Planning Group to Build Accountability

1. Clearly define the goals and purpose of the group. The goals should define, discipline, and drive the group, its functions, and its philosophy. The goals should energize members to pursue their purpose by the most effective means possible.
2. Carefully select the co-chairs. Selecting the most qualified, experienced co-chairs is key because strong leadership is essential to effective group functioning.
3. Ensure effective goal-setting, strategic planning, and monitoring of progress/activities within the group. Translating a goal into specific tasks and activities is critical to group accountability. This process creates a framework for setting priorities, allocating resources, evaluating progress, and revising plans.
4. Ensure effective feedback and evaluation regarding task accomplishment and process. The group has the responsibility to establish mechanisms for obtaining feedback from members on whether its activities are leading toward accomplishing the goal and on problems that arise to impede the process.
5. Regularly review the performance of the co-chairs, and the heads of committees and subcommittees. One of the most difficult tasks of a group is regularly appraising its performance. It is important for group cohesion and trust, however, to determine how well each group member in a position of power is functioning.
6. Monitor the effective use of all resources available to the group. The group has the responsibility to monitor HIV prevention community planning funds and to share resources with each other.
7. Serve as a court of last resort for complaints. The group should ensure that they have developed structures and processes that guard against arbitrary decision-making and discriminatory behavior, as well as procedures to resolve complaints and conflict.
8. Insist on the transparency of the group. As a publicly-funded entity, the group has the responsibility to be open to public scrutiny and to report on their activities and findings. Conflict of interest policies should be developed to ensure the integrity of both the individual members and the group as a whole.
9. Organize the group to be efficient and effective. The planning group will consist of members who have busy schedules and other commitments. Time will be an issue for all members. In assessing their use of time, the group should consider: Are they hearing not only the good but the bad news (hearing about problems or conflicts) from the co-chairs and committees? Is it making effective use of committees or working groups? Are meetings productive? Are timelines being managed well? Are members able to meet their commitments?
10. Establish a group culture of openness, trust, and candor. In being accountable, members should consistently reaffirm the duty to face, not hide, from problems. The group should strive to create a climate in which problems will be aired, differences expressed, and solutions sought within the context of moving toward achieving the group's goals.

Adapted from Bell, 1993.

# THE HISTORY OF THE UNITED STATES

The history of the United States is a story of growth and change. From the first settlers to the present day, the nation has evolved through various stages of development. The early years were marked by exploration and settlement, followed by a period of rapid expansion and industrialization. The American Revolution was a pivotal moment in the nation's history, leading to the establishment of a new government and the declaration of independence. The 19th century was a time of great change, with the Civil War and the Reconstruction era shaping the nation's future. The 20th century has been a period of significant progress, with the United States becoming a global superpower and a leader in science and technology. The challenges of the future are many, but the spirit of innovation and progress that has defined the United States from its beginning remains a constant force.

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- Encourage open, facilitated discussions in which all participants feel free to speak up.
- Be willing to take risks.
- Build on previous planning successes.
- View this not only as a tremendous challenge but also as a tremendous opportunity to improve HIV prevention programs.



## Chapter 3

# Conflict of Interest and Dispute Resolution

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2. Valuing and Managing the Community Planning Process	5. Assessing and Setting Priorities for Community Needs	
3. Conflict of Interest and Dispute Resolution	6. Setting Prevention Program Priorities	
	7. Selecting Among HIV Prevention Interventions: Theoretical Basis, Effectiveness, and Cost-Effectiveness	
	8. Evaluating the Community Planning Process	



# Chapter 3

## Conflict of Interest and Dispute Resolution

### 3.1 OVERVIEW

The framework of diversity for HIV planning necessitates an understanding of how to deal with conflicts and disputes that may arise in the planning process. HIV prevention planning groups must be ready to face two general types of conflicts: 1) financial conflict of interest issues and 2) disputes among planning group members. Before the planning process begins, processes should be developed to deal effectively with the challenges created by conflict. The *Supplemental Guidance* underscores the need for advance planning by requiring each grantee or planning group to adopt "specific policies and procedures for resolving disputes and avoiding conflict of interest."

In this chapter, each type of conflict is examined from several perspectives. Conflict of interest is examined first and a variety of suggestions are given about how to define it and where to look for it in the planning process. The discussion concludes with a series of suggestions about how to prevent conflict of interest from occurring and what to do if it does arise.

The discussion of dispute resolution begins with a look at different kinds of conflict and how to prevent unnecessary and destructive conflicts from occurring. This section explains how to create a working environment that minimizes group disputes. This

section also offers a series of principles and techniques for dealing with conflicts that have escalated into disputes. Alternative approaches are given so that the strategy chosen will be appropriate for both the nature of the problem and the group.

The chapter concludes with a section entitled, "Notes from the Field: Conflict of Interest and Dispute Resolution," which summarizes findings from interviews with state AIDS directors and other project staff regarding their experience with this issue in planning groups.

### 3.2 CONFLICT OF INTEREST

Conflict of interest generally refers to situations in which an individual stands to gain personal benefit (usually financial) from participation in government decision-making. Planning groups will need to determine how they will define conflict of interest. Various definitions can be developed; the following were used by Ryan White CARE Act Planning Councils (HRSA, 1992).

**Definition #1:** "A conflict of interest occurs when an appointed official knowingly takes action or makes a statement intended to influence the conduct of the public body of which she/he is a member in such a way as to confer any financial benefit on the member, family member(s), or on any organization in which she/he is an employee or has a significant interest."

**Definition #2:** "A planning council member who also serves as a director, trustee, or salaried employee, or otherwise materially benefits from association with any agency which may seek funds from the planning council is deemed to have an 'interest' in said agency or agencies."

Although HIV prevention community planning groups will not be making direct decisions about how

#### Definitions

**Conflict**—An expressed opposition between two or more parties.

**Dispute**—A conflict in which the parties involved have openly quarrelled or disagreed and, in some way, moved the problem into a public arena.

**Conflict of interest**—A conflict between one's obligation to the public good and one's self interest.

money will be spent, they will be engaging in advisory activities that could have significant impact on funding decisions. As a result, there clearly will be situations in some planning groups where conflict of interest questions will arise. However, the challenge can be successfully managed so that most potential conflicts of interest are avoided, and ones that do occur are dealt with effectively and fairly.

### 3.2.1 Types of Decisions That Can Cause a Conflict of Interest

One of the first tasks assigned to the planning group is to "assess existing community resources for HIV prevention to determine the community's capability to respond to the epidemic." This assessment, which is intended to survey the entire range of prevention activities and will involve making judgments about the effectiveness of various institutions, organizations, and community groups, is a prime area for possible conflicts of interest. It is possible that some group members will not be able to make objective assessments of existing resources because they are too involved in an effort that is being studied.

A second area where conflicts of interest may arise is in the examination of needs and the group's effort to prioritize them. This is probably the most delicate task the planning group has to perform. Recommendations for funding will be developed out of these priorities and that makes the potential for financial conflict much more obvious. Also, decisions that are made on priorities are much more likely to involve voting or alternative situations where there is the potential to influence others.

Evaluating group activities is a third potential source of conflict of interest. Planning groups are required to evaluate the process used by the group and, in the future, will be called upon to analyze and evaluate programs they have supported in previous years. These evaluations clearly will have an impact on future decisions and could be influenced by rivalries among individuals who are affiliated with specific organizations or institutions.

### 3.2.2 General Principles for Dealing with Conflict of Interest

The essential principles for dealing with conflict of interest issues are openness and personal responsibility. People's suspicion of conflict of interest is often greater than its reality, and anything less than com-

plete disclosure of all relevant information can serve to fuel charges and accusations. Each HIV prevention planning group member needs to be open about and take personal responsibility for acknowledging conflict of interest issues.

### 3.2.3 Preventing Conflict of Interest from Occurring

Planning groups that think ahead about possible conflicts, and then adopt specific strategies for dealing with them, should be able to avoid disruptive conflicts of interest. Listed below are eight different strategies for preventing conflicts of interest from occurring (HRSA, 1992). Groups should decide which are most appropriate for their situation:

**3.2.3.1 Recognize Conflict of Interest When Making Appointments.** Many conflict of interest problems can be avoided by using caution and common sense in the appointment process. Some individuals in the community may be too deeply identified with a particular organization or institution to avoid having conflicts of interest. Other individuals, who have similar expertise but are not as directly involved with a particular organization, may find it easier to participate without conflicts of interest. In either case, it is important to clearly define members' role in the decision-making process.

Some planning groups with similar functions have sought to ameliorate this problem of conflicting interests by emphasizing that people are being appointed for their general expertise and not as representatives of specific organizations or institutions. This focus does not eliminate conflict of interest issues, but it can help alter the manner in which people view their roles in the group. Emphasizing the cooperative spirit of those appointed diminishes the sense that group members are using the process for their own gain.

**3.2.3.2 Develop Conflict of Interest Guidelines for Group By-Laws.** These guidelines should be carefully thought out and developed in consultation with a lawyer and/or other individuals who have experience with conflict of interest issues. Once developed, the guidelines should be made readily available to all involved with the planning process. Planning groups should include the conflict of interest guidelines and procedures in their by-laws as an integral part of the overall rules by which the group will function. Sample by-laws developed by HIV planning bodies are shown in Table 3-1.

The guidelines each planning group should use in developing conflict of interest by-laws should cover the following topics:

### **Table 3-1: Sample Conflict of Interest By-laws**

Below are examples of bylaws developed by HIV planning bodies to address conflict of interest. These may be useful to HIV prevention community planning groups in crafting by-laws to meet their own requirements.

#### *Sample by-laws:*

##### **Conflict of Interest**

1. In making recommendations to the Department of Health Services concerning priorities, the planning group must operate in compliance with all applicable state and local conflict of interest laws. In order to safeguard the planning group's recommendations from potential conflict of interest, each member shall disclose any and all professional and/or personal affiliations with agencies that may pursue funding. A Disclosure Statement form will be completed by each group member and kept on file. On issues where a group member's affiliate is the potential recipient of funds, that member may not vote or participate in the discussion. Instead other members of that agency, who are not planning group members or alternates are encouraged to take part in the discussions.

2. Administrative Agency shall develop and publish a policy and procedures regarding conflict of interest. Said policy and procedures shall be developed in order to safeguard the Committee's recommendations and actions from potential conflict of interest. Each member shall disclose any and all professional and/or personal affiliations with agencies that may pursue funding. On issues where a Committee member's affiliate is the potential recipient of funds, that Committee member may not vote or participate in the discussion.

Before his/her first meeting as a member of the Committee, each member shall disclose in writing any and all professional client or personal affiliations with agencies that may pursue HIV prevention funding. A Disclosure Statement form shall be completed annually by each Committee member and kept on file.

- a definition of conflict of interest that the group will use;
- a summary of the purpose of the guidelines;
- an explanation of the type of financial disclosure required of group members;
- the general approach the group will use in handling conflict of interest issues; and
- the identification of who in the group will have primary responsibility for addressing conflict of interest.

3.2.3.3 Define Process for Review of Conflict of Interest. It is important to have clear guidelines that explain how conflict of interest will be dealt with in the planning group (see Section 3.2.3.1). In addition to these general guidelines, it is helpful to agree in advance on the review process that will be used if conflict of interest issues do arise. Such preparation will help to insure that standard procedures are used and that all charges are dealt with in a consistent manner.

Items to consider in developing the review process include:

- the procedures for initiating a review;
- the persons involved in the review process;
- the specific steps to follow; and
- the role (if any) of legal counsel.

3.2.3.4 Conduct an Orientation on Conflict of Interest. Another way to raise conflict of interest issues is to begin the group process with an orientation program for introducing questions and issues around possible conflicts of interest. During the orientation, participants can determine which guidelines for dealing with conflict of interest should be adopted as group policy.

3.2.3.5 Assign Responsibility to a Specific Committee. Giving responsibility for conflict of interest issues to a specific committee provides a planning group with a readily available means to act if necessary. This can build member confidence that the issue is considered important and the group has a clear method for addressing it.

3.2.3.6 Authorize All Members to Initiate a Review of Potential Conflicts of Interest. Confidence in a group's procedures for dealing with conflict of interest will also increase if each member has the authority

to propose questions of conflict of interest for review. Without this general authority, some individuals might charge that a group is trying to control who can or can not speak on issues of conflict of interest.

**3.2.3.7 Require Conflict of Interest Forms.** Each planning group should prepare a form that asks basic questions about the organizations and institutions with which members are affiliated (See sample form at end of chapter). These questions should focus on obtaining information about activities related to HIV prevention and other areas of health care. Group members should specify their level of involvement within an organization to help indicate the potential for a conflict of interest. Part-time volunteers, for example, will have a very different relationship with an organization than a salaried staff member or a member of a board of directors.

The disclosure forms should be collected as the planning groups begin their work and should be kept by the committee responsible for monitoring conflict of interests. The forms will help anticipate possible conflicts of interest and can be accessed by concerned participants when a conflict of interest is in question.

**3.2.3.8 Establish Means for Removing Members Who Are Uncooperative With Conflict of Interest Inquiries.** In dealing with a member who does not cooperate with conflict of interest inquiries, one option is to agree in advance on a procedure for removing such a person from the planning group. Such action should take place only in extreme situations where an individual has refused to abide by the established guidelines and shows no willingness to change behavior. Any agreement on the means for removing a member from the planning process should be included in the by-laws relating to conflict of interest.

### 3.2.4 How to Identify and Address Conflicts of Interest

The group must determine what sort of activity should be permitted if a conflict of interest is found to exist. Types of questions every group should ask include:

- Should a member with a conflict of interest be prohibited from discussing an issue or only from voting on it?
- If someone has a conflict of interest, should they be allowed to participate in the needs assessment activity?

- Is the process of prioritizing needs and interventions too closely related to funding decisions or can a line be clearly drawn between allocating funds and proposing high priority strategies?

In order to sort out the many difficult questions associated with conflicts of interest, planning groups may need the help of legal counsel. Groups may wish to establish a relationship early on with a qualified attorney who can assist them at various stages. Ideally, groups may find an attorney who works for one of the state or federal agencies represented in the planning effort. An alternative approach for receiving legal advice on conflict of interest is to inquire at law firms for an attorney willing to do pro bono work for the community.

Legal counsel can play an important role in clarifying the meaning of local, county, and state statutes regarding conflict of interest. Many states and localities have elaborate regulations governing this issue and legal counsel can determine how these are applicable to the HIV prevention community planning process. Furthermore, legal counsel can provide professional and objective judgments regarding what constitutes a conflict of interest and how to deal with specific instances that arise.

If members have a conflict of interest, a basic strategy to follow is to prohibit them from voting on the specific issues in question. The best way to implement this policy is for members to announce their conflict and abstain voluntarily. This approach encourages members to take personal responsibility for identifying and acting upon any conflicts of interest they may have.

In other instances, the group may find it necessary to impose abstention on a member by referring to the policies and procedures that govern conflict of interest. Such group action will help to keep specific decisions from being unduly influenced. However, this may cause other problems if it creates divisions among members. Therefore, the group should act to force abstentions only as a last resort when other voluntary efforts have failed.

## 3.3 UNDERSTANDING THE NATURE OF GROUP DISPUTES

To develop an inclusive approach for addressing the HIV prevention needs of a particular community, it is essential that a wide range of representatives participate in the planning process. This breadth of perspectives will ensure a program



that takes all aspects of the community's needs into account. This same diversity, however, will inevitably lead to differing ideas for the content, structure, implementation, and other aspects of an HIV prevention plan. Similarly, there may be situations where multiple planning groups in one project area find themselves in conflict with each other over the various plans that they have developed and recommended.

Disputes within the planning process need not result in an ineffective meeting, uncomfortable tension level between participants, or a stalemate. Conflicts are inherent and essential to working together. Too little conflict in a group can be just as detrimental to the group's success as too much conflict. The essential mindset for approaching a dispute involves recognizing how to fully use and address the differences that have surfaced. Efforts should focus on redirecting the energy of a conflict into developing effective plans for the community.

### 3.3.1 Positive and Negative Aspects of Conflict

Maintaining a constructive approach to conflict in a group produces many positive outcomes. The diverse points of view increase the information flow and stimulates participants to think on many different levels. Work and performance of individuals, as well as groups, improve when dynamic thinking and processing replace reactive or stagnant positions.

Unresolved conflicts, however, can seriously impede a group's ability to work together and will shift the group's focus away from the goal of HIV prevention. Allowing the negative aspects of conflict to dominate a dispute creates an atmosphere of suspicion and distrust in the working relationships. People fear their concerns will not be accounted for or heard; therefore, the development of the group suffers from uncooperative or withheld participation. Ultimately, destructive approaches to conflict lead to misunderstandings, confrontations, and even group gridlock.

### 3.3.2 Sources of Group Dispute

A critical step in using and responding to conflict involves understanding the sources from which disputes arise. For example, a situation in which two parties arrive at different needs assessments for their same community would be handled differently than if two parties continually misinterpret each other's statements. By understanding the source of a conflict, groups can determine how best to prevent disputes or

respond to them when they first materialize. As shown in Figure 3-1, disputes arise from conflicts in five different areas: data, relationships, interests, structure, and values (The Conflict Clinic, 1991).

Data conflicts can result from a lack of information or the presentation of misinformation. For example, in reviewing incompatible needs assessments for the same community, divergent views may have resulted from using different sources of information or different means of analyzing the same information. Although statistical data are often thought to be objective, subjective interpretations can lead to multiple conclusions.

Relationship conflicts develop around the interpersonal dynamics of working together. An environment that encourages interaction among participants depends upon the level of communication. Stereotypes or misperceptions that individuals bring to the planning process will often hinder the flow of communication. Representatives from different segments of society may find it difficult to express their concerns for fear of the perceptions they believe others have of them. When honest communication cannot take place, concerns become manifested elsewhere and important considerations go unheeded. Strong emotions, either denied expression or untempered, also can affect the ability individuals have to relate to one another in the group setting.

Interest conflicts can involve differences in substantive interests, procedural interests, or psychological interests. Members of the HIV planning group might share a goal of preventing AIDS; yet, a substantive interest conflict may arise as participants determine and prioritize the specific needs of their community. A conflict due to procedural interests may occur if group members oppose one another on how to implement prevention programs. Perceived or actual competition of psychological interests may also lead to disputes. Psychological interests are need-based and seek to protect a group or individual's identity, security, community, and vitality.

Structural conflicts are built into the group's interaction from the beginning. This is different from relationship conflicts, which can evolve throughout the duration of the group's time together. Sometimes structures may be intentionally shaped to make certain parties feel at a disadvantage. Other structural aspects, however, could have no ulterior motives yet still lead to conflicts. For example, the time and place of the planning sessions, chosen out of convenience, could disrupt the cohesiveness of a group if some members feel disproportionately inconvenienced.

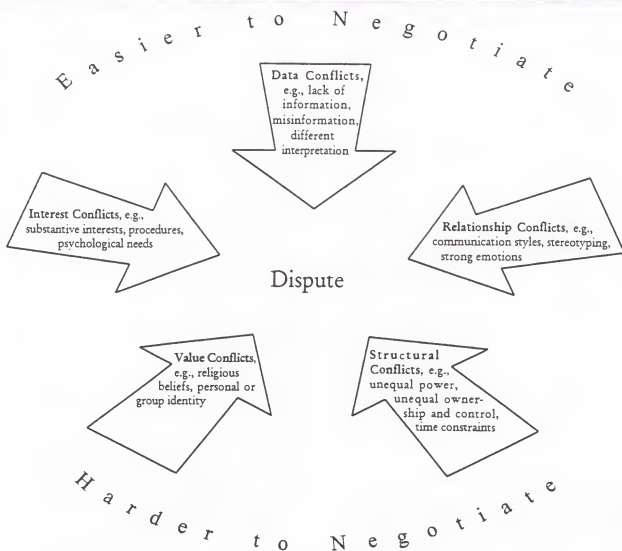
Value conflicts can develop into extremely intense disputes if the values of the separate parties are closely linked to their personal or group identity. People adhere strongly to their values, which are shaped by different ways of life, ideology, and religion. Often, people construe the proclamation of values apart from their own as a threat or renunciation of the values that have been an intrinsic part of their lives. For this reason, it is important to recognize that differences in values are not negotiable or subject to resolution. When there is a conflict of values, participants are not expected to relinquish their values but to learn how to respect different beliefs while still working toward

the shared concern of HIV prevention. An obvious example of this is the way in which an individual's religious beliefs may shape the way that he or she thinks about sex or drug use. Other group members should not try to change those values, but, rather, to find a way to acknowledge them and still search for ways to work together.

### 3.3.3 Possible Responses to Disputes

There are several different response styles to conflict that can be appropriate or inappropriate depending on the source and nature of the dispute. These

**Figure 3-1: Sources of Group Dispute**



This chart was created from material contained in "An Introduction to Negotiation and Conflict Resolution." Institute for Conflict Analysis and Resolution. Fairfax VA; George Mason University, 1994. The material was adapted from concepts developed by Dr. Chris Moore in, *The Mediation Process*. San Francisco: Jossey-Bass, 1986.

include avoidance, appeasement, domination, and balanced (Schindler and Lapid, 1989). The avoidance approach to conflict can be either active, such as suppression, or passive, such as denial and neglect. If certain sensitive topics are avoided for fear of engaging in a value conflict, the members deny that the potential for a dispute exists. Avoiding the expression of conflict decreases the level of confidence that group members develop in their ability to address and handle difficult situations in their interactions.

In contrast to the avoidance approach, a person who uses an appeasement style to respond to disputes takes on the attitude of accommodating the other side at whatever cost. This approach appeals to many as flexible and generous, and in certain situations may be necessary if time and resources are limited. However, appeasement does not address the cause of the conflict. When only the symptoms of a dispute are treated, the conflict may worsen and repeat itself. Through constant appeasement, working relationships suffer from being used as a bargaining piece. A participant who continually makes concessions in hopes of preserving healthy relationships actually undermines the representative nature of the group.

A dominant style frames conflict as a competition and reacts accordingly. By viewing a dispute as a win/lose situation, conflicting parties feel the need to somehow overpower one another. This response style jeopardizes working relationships and also masks the substantive issue as both sides define it. The dominant style enforces its perception and therefore stifles the creative potential of others in the group.

A balanced approach to conflict should be employed whenever possible in response to group disputes. From a balanced perspective, a person retains his or her point of view while still remaining receptive to another's ideas. Therefore, participants resolve their disputes by addressing the root of the conflict, while still respecting relations with opposing parties. This allows for all concerns to be voiced and explained rather than ignored or misperceived. Within the balanced style of responding to disputes are two different approaches: compromise and collaboration.

- **Compromise:** Compromise implies a give and take process. This technique is most useful when cooperation is important for maintaining comfortable working relations. Time or resource constraints could lead to a resolution of a dispute that does not fully meet all expectations, but is a solution with which all members agree.
- **Collaboration:** When participants collaborate to

solve a problem, they begin with the realization that their original views may be changed as the group progresses. Cooperation and creativity guide the participants to discover ways of resolving their problem so that concerns and expectations of all parties are met. Given sufficient time and resources, collaboration frames the conflict in such a way that neither party incurs a loss and a win/win situation results.

### 3.4 CREATING A CLIMATE FOR DISPUTE RESOLUTION

Responding to disputes within the planning group will be aided by fostering a climate conducive to dispute resolution. A proper climate allows member differences to add to rather than detract from the process of devising an effective HIV prevention program. Furthermore, this climate establishes a safe environment of mutual respect that increases honest exchanges between individuals. As participants increasingly trust one another, a commitment to working together develops so that the group agrees to work through the hard parts of the planning process. The growth of trust throughout the planning process strengthens the interpersonal relationships needed for working together.

#### 3.4.1 Developing Communication and Listening Skills

Communication skills, particularly the often under-practiced skill of listening, are essential for creating an effective work environment. When disputes arise, the extent to which participants feel confident in their communication skills will determine how readily the conflict can be diagnosed and resolved. Communication encompasses both articulating and listening skills; it involves the expression, reception, and interpretation of a message. A breakdown in any stage of the communication process results in miscommunication, which usually leads to unnecessary conflict. In developing communication skills, representatives in the group process need to avoid prematurely concluding a discussion on an issue of concern. If dismissed too quickly, the issue may still reside in the minds of representatives who do not feel the group completely acknowledged or addressed the heart of the matter. One-way transmission, assumed by either the speaker or listener, also creates barriers to successful communication. The speaker may believe he or she is communicating yet never intends to listen in response. The listener may also create a one-way dis-

cussion if he or she does not attend to the flow of information from the speaker before responding. In addition, mixed messages can impede the genuineness of communication. Inconsistent purposes or emotions, for example, shade the relevant information needed for honest communication.

Developing communication skills, both speaking and listening, will promote a dialogue format for the group process. Dialogue differs from discussion or debate because it involves all parties. Both the speaker and the listener(s) assume responsibility for the exchange. A dialogue forum necessitates the willingness to listen and to learn from each other. Several basic principles are at the heart of dialogue:

**3.4.1.1 Establish Ground Rules for Effective Communication.** An important step in developing communication involves making agreements that will guide the group dialogue regarding HIV prevention. As the group convenes, participants should develop and decide upon the rules they want the communication process to follow. In establishing an understanding of expected behavior at the beginning, the ease with which people share their true thoughts and feelings will increase. If emotions rise into a heated argument, taking a moment to restate the ground rules provides an objective framework for redirecting the energy of the exchange. Furthermore, many instances of miscommunication may be avoided by insisting that people be conscious of their own communication style (Schindler, 1988).

It is important for each group to devise and agree on its own set of ground rules in order to ensure group ownership of them. Possible ground rules to consider are:

- Be open to learning from each other's point of view.
- Be willing to listen, do not interrupt.
- Share group time fairly.
- Use precise language and avoid exaggeration.

**3.4.1.2 Listen with Empathy.** This technique involves active listening where undivided attention is given to the speaker. Listening actively requires the receiver to avoid the urge to formulate his or her own answers but to devote the listening time to processing what is being said. Real listening requires the receiver to relinquish a concrete agenda and allow a certain spaciousness in the dialogue.

Empathy is at the root of dialogue. Empathy is defined here as the willingness and ability to recreate another's point of view (Schindler and Lapid, 1989). If the listeners in a group put themselves in the role of the speaker, the concerns can become shared by the group and therefore stand a better chance of being resolved. For instance, if group members can begin to see what it would be like to be someone from a different ethnic group or to have a different sexual orientation, then disputes relating to those issues can be treated with greater sensitivity and skill.

**3.4.1.3 Restate with Understanding.** Restating with understanding follows active listening as a technique for improving communication skills. This is a method groups can use when communication seems to be breaking down between some members. The chair can suggest that members who appear to be in opposition take time to restate each others' views. This restatement is not an expression of opinions or judgments about the message but an effort to check for complete understanding. Each speaker then has the opportunity to clarify a message that was misinterpreted.

The clarification stage verifies that both parties in the dialogue are talking about the same thing and at the same level. Many times when misperceptions have escalated into a dispute, the situation can be rectified and new insights discovered by having participants clarify how they are processing the exchange in conflict. Understanding in this exchange does not necessarily mean agreement; however, it is an essential precursor to agreeable decisions.

**3.4.1.4 Speak One's Truth.** The speaker in the dialogue process must also assume responsibility for communicating his or her message clearly (Schindler and Lapid, 1989). Improper use of language that connotes various meanings can lead to misperception or even polarization within the group. A speaker may claim the group is not listening, but the speaker may not be saying what he or she really means. As one must listen with empathy, so must one speak with empathy in order to reach mutual understanding. This entails the ability to express oneself fully while simultaneously attending to how other people are receiving the message.

Speaking one's truth is a skill that involves expressing one's point of view persuasively but not coercively. Persuasive speech rather than coercive messages relays the speaker's intent to contribute to and learn from the communication process. Coercive messages cause the listeners to feel forced into agree-

ing with a point of view. The speaker places pressure on the listener with coercion formulas such as "you must do this," or "you must think this." Honest persuasion, however, conveys a reciprocal interest in increased understanding. The speaker uses "I" statements to share with the group his or her own belief and remains open to the "I" statements of others.

**3.4.1.5 Balance Reason and Emotion.** Effective communication also requires a balance between reason and emotion. Both the speaker and listener must establish this balance in the exchange. Messages that are sent and received have both a rational and an emotional content. If emotional feelings are allowed to control a message, judgments could be clouded. On the other hand, masking emotions or denying them will decrease full understanding and impair the level of motivation for continuing with the group process. Reason must channel and temper emotion while emotion informs and energizes reason (Brown and Fisher, 1988).

### 3.4.2 Bridging Differences to Build Working Relationships

Establishing and sustaining healthy working relationships is an ongoing and intense process but critical for the group's effectiveness. Sound decisions depend upon expressing different opinions, scrutinizing various sources of evidence, and thoroughly examining all proposed alternatives. In order to bridge these differences and expand the group's knowledge base, it is important to encourage a spirit of open inquiry. Maintaining an open mind relies upon a certain tolerance for ambiguity, for acknowledging the truths in alternate perspectives without insisting on "either/or" conclusions. Suspending pre-judgments creates a safe environment where there exists the ability to honor differences and members can agree to disagree.

### 3.4.3 Cultural Differences in Dealing with Conflict

Culture can be broadly defined as a group to which one identifies due to customs, traditions, mores, behaviors, environments, or beliefs. Under this definition, race, ethnicity, gender, socioeconomic status, sexual orientation, and physical ability can all be factors that determine a culture. Understanding cultural tendencies provides a framework for thinking about how cultural differences can affect group interactions.

There are several ways in which cultural differences can influence how individuals deal with con-

flict. One source has suggested that these differences are of seven different types (The Conflict Clinic, 1991):

- attitudes toward conflict
- communication styles
- comfort with disclosure
- problem-solving approach
- decision-making styles
- task completion
- expectations regarding outcomes

An awareness of the intrinsic value of the differences that fall along cultural lines grants the group process unlimited perspectives from which to design the most viable prevention programs. Cultures should not be stigmatized as the majority or minority, for this automatically assumes a hierarchy of importance or power.

If cultural differences begin to strain rather than enhance working relations, an effective exercise involves forming "culture caucuses." In these small groups, representatives can express in a familiar environment their concerns about working with representatives from different cultures. The caucuses will present the opportunity for clarifying the needs of the separate cultures and for determining ways of meeting the concerns of the various groups within the larger planning group. Caucuses serve to remind representatives that they can maintain their identity while still being open to the views and ideas of others.

An additional method for building cultural awareness within the planning group is to schedule opportunities for developing cultural sensitivity and for learning about the various cultures represented in the group.

## 3.5 PRINCIPLES OF DISPUTE RESOLUTION

Despite careful prevention efforts, the disagreements and conflicts that inevitably result from working with people of diverse perspectives may turn into disputes. However, if representatives draw on specific principles for working together toward "win/win" outcomes, then disputes can be successfully addressed so that they do not recur or impede the overall group planning effort. Table 3-2 lists seven principles of dispute resolution.

1. *Establish a Goal that Includes the Concerns of All Involved:* Identifying and maintaining a focus on a clearly stated common goal is a powerful way to keep people on track when they are trying to resolve a dispute. Individuals will tolerate differences and make extra efforts to reach agreement if they know they are committed to the same goal. This is particularly true if the goal involves community service or is in support of some deeply held set of values or beliefs.

2. *Maintain a Climate of Fairness and Mutual Respect:* A sense of fairness is essential to any effort to resolve a conflict. Participants in a dispute will not initiate or continue procedures for considering their disagreements, unless they believe the process is fair. When people have disagreements they become particularly sensitive to whether or not others are really listening to them and considering their ideas.

Therefore, it is essential to pay close attention to both the structure and tone of dispute resolution efforts. The structure of the process must give all participants equal time and opportunity, and the tone of the dialogue must be one of mutual respect.

3. *Distinguish Between the Person and the Problem:* If participants in a dispute view themselves as adversaries in a face-to-face confrontation, it is difficult to separate their relationship from the substantive problem. As a result, each side tends to become defensive and reactive and to ignore the other side's legitimate interests altogether. Therefore, it is essential to structure dispute resolution efforts in ways that allow participants to focus on the problem at hand, not on the other person (Fisher and Ury, 1981). This is particularly true in disputes that involve a great deal of emotion such as those related to race, sexual orientation, or religion. In these types of disputes, it is essential that group members not allow their disagreements to lead to stereotyping or to escalate to other forms of personal attacks.

4. *Identify and Build Upon Areas of Agreement:* Identifying areas of agreement shared by a group plays a foundation on which the group process can build solutions to disputes that occur. Disputes often leave groups feeling disjointed and polarized because the existing conflicts become the entire focus of group activity. Therefore, efforts at dispute resolution should continually strive to reorient the group toward all that it has in common.

Group co-chairs can also help to develop a sense of cooperation by pointing out any new agreements

### Table 3-2: Seven Principles of Dispute Resolution

1. Establish a goal that includes the concerns of all involved.
2. Maintain a climate of fairness and mutual respect.
3. Distinguish between the person and the problem.
4. Identify and build upon areas of agreement.
5. Distinguish between interests and positions.
6. Develop options for mutual gain.
7. Use objective criteria.

that are identified by the group. This is particularly helpful when a group agrees on part of a problem statement or strategy, but not the entire thing. Reminding group members what they do agree on can help them stay focused until they find a way to agree on an action they should take together. For example, planning group members might agree that educating teenagers about how to prevent HIV infection should be a high priority and yet, at the same time, have very different views about how that education should take place. In such a situation it is extremely important to keep members focused on the fact that they agreed on an important priority and that their task is now to find specific ways to implement it.

5. *Distinguish Between Interests and Positions:* Disputes generally appear to be the result of conflicting positions and, therefore, most people focus their dispute resolution efforts on narrowing the gap between the different positions that have been presented. However, the basic problem in dispute resolution lies not in conflicting positions but in the conflict between each side's interests (i. e., their needs, desires, concerns, and fears).

The difference between basic interests and positions is clearly illustrated in an often used story of two men quarreling in a library. One wants the window open and the other wants it closed. Theyicker back and forth about how they can compromise with each other. Should they leave it open a crack, half-way, or three-quarters of the way? No solution satisfies them both. Enter the librarian. She asks one why he wants the window open: "To get some fresh air." She asks the other why he wants it closed: "To avoid the draft." After thinking for a minute, the librarian



opens wide a window in the next room, bringing in fresh air without a draft. (Fisher and Ury, 1981)

The librarian could not have invented this solution if she had focused only on the two men's stated positions of wanting the window open or closed. Instead, she looked at their underlying interests of fresh air and no draft. This crucial difference between positions and interests enabled her to devise a way to resolve their dispute.

One can identify the interests involved in a dispute by listening deeply and seeking to ascertain what is behind the stances or positions of the parties involved. Through asking the right questions and carefully analyzing the responses, it is possible to discover what people really require instead of just what they say they want. The ability to make this crucial distinction can often be the key to finding solutions to seemingly intractable problems.

**6. Develop Options for Mutual Gain:** This principle capitalizes on the realization that interests may be met through a variety of means. Freeing participants from stagnant positions taps into the creative potential of the group, whereas holding firmly to positions and premature judgments prevent complete understanding.

The first step toward discovering options that address the needs of all concerned is to hold an informal brainstorming session. Representatives should be encouraged to list as many solutions and ideas as possible without passing judgement. This process frees members to produce ideas unfiltered by their own or other's experiences. In this way, new options can be created. After the initial brainstorming session, promising ideas can be highlighted and a second phase of collaborative thinking can occur. In this stage, ideas are examined and clarified for their ability to satisfy all parties in the dispute (Susskind and Cruikshank, 1987).

**7. Use Objective Criteria:** Using objective criteria as a means of helping to resolve disputes greatly increases the likelihood of being able to reach an agreement that has both wisdom and stability. Participants in a dispute who agree to use standards such as fairness, effectiveness, and factual or scientific merit have taken a big step toward finding a way out of their impasse. Other criteria that can provide objective guidance might be based on precedent or perhaps community practice. Using objective criteria makes it easier to shift the focus of discussion from what the two sides are willing to do to the question of what ought to be done (Fisher and Ury, 1981).

## 3.6 ALTERNATIVE APPROACHES TO DISPUTE RESOLUTION

There are a wide variety of strategies and approaches to use in dealing with disputes that will develop during the planning process. Each of them uses some or all of the basic principles of communication and dispute resolution that are described in the previous sections. Some approaches are designed to be used in the early stages of a dispute and others are more appropriate for disputes where positions have hardened and a situation has become polarized. Tables 3-3 and 3-4 present a checklist of key steps to take when a dispute arises and a summary of some possible approaches to common group disputes.

Each group must choose the approach most appropriate to their need at a particular time. In determining the approach a group should use to handle a particular dispute there are at least two important factors to consider:

- the nature of the disagreement, and;
- the basic dynamics that currently exist in the group.

Settling disputes in a manner that is satisfactory to all involved protects working relationships and minimizes future problems. The emphasis in this section is on approaches to dispute resolution that, as much as possible, meet the needs of all parties who are in conflict. Therefore, these methods are referred to as "win/win" as opposed to "win/lose" approaches to problem solving. Another important aspect of the approaches described here is that all of them except one rely on those involved in the dispute to agree among themselves about what should be done to resolve it. This agreement increases the likelihood that group members will abide by decisions and reduces the chance that resentment will grow because of a forced settlement.

### 3.6.1 Process Consultation and Coaching

An initial step that can be taken when disputes begin to arise is to seek consultation or coaching on how to improve group process. Many times, disputes seem more serious than they are because some in the group feel that they are not being listened to or given a real opportunity to state their views. If this is the case, then minor adjustments in how meetings are run can often help to keep a conflict from escalating. The group may wish to consult with an independent expert in communication and problem solving to get specific suggestions on improving the group process.

**Table 3-3: Conflict Checklist**

This checklist is designed for highlighting key steps to take when a conflict has escalated into a dispute.

**1. Look for the sources of the conflict**

- ☐ financial interests
- ☐ data
- ☐ relationship
- ☐ interest
- ☐ structural
- ☐ value
- ☐ cultural differences in addressing conflict

**2. Evaluate the group's ability to respond**

- ☐ determine characteristic response styles to conflict
- ☐ assess the climate of the group: communication skills and ability to bridge differences

**3. Analyze the dispute situation**

- ☐ number of people involved
- ☐ state of working relationships
- ☐ ability of members to be objective
- ☐ intensity of the problem; the balance between reason and emotion
- ☐ how long the problem has persisted
- ☐ consequences for all parties
- ☐ level of agreement beyond the apparent disagreement
- ☐ existence of objective criteria for addressing dispute

**4. Develop a win/win solution**

- ☐ establish a common goal
- ☐ maintain fair climate of mutual respect
- ☐ distinguish between people and the problem
- ☐ identify and build on areas of agreement
- ☐ focus on interests behind positions
- ☐ use objective criteria
- ☐ explore options for mutual gain

**5. Determine appropriate strategy**

- ☐ process consultation and coaching
- ☐ data exchange meeting
- ☐ joint problem solving
- ☐ negotiation
- ☐ mediation
- ☐ Ten-Step mediated dialogue
- ☐ non-binding third-party recommendations
- ☐ third-party decision-making

**3.6.2 Data Exchange Meeting**

Some misunderstandings and disagreements that occur are based solely upon different uses and interpretations of data. In the HIV prevention community planning effort, these disagreements are most likely to occur early in the process as groups assess and prioritize the needs of the community. A data exchange meeting, with either the entire planning group or a representative sub-group, can identify how to overcome data-related disputes. One of the most important tasks of a data exchange meeting is to agree on criteria that will be used to seek additional information and then to propose specific steps for obtaining the information and a timetable for doing so.

**3.6.3 Joint Problem Solving**

Joint problem solving is an informal meeting of concerned parties to resolve a question or issue of mutual concern. This is an approach that can be used in the early stages of a dispute before it has become highly polarized. The purpose of this type of meeting is to change a disagreement from an adversarial confrontation to a side-by-side problem-solving discussion (Jones, 1994).

A joint problem-solving session will generally involve only a portion of the group, but, in some instances, could also work effectively with the entire group. The session itself should be chaired by someone in the group who is skilled at leading meetings and who is perceived to be neutral on the dispute in question. The person facilitating the session should then guide participants through an informal discussion that 1) analyzes the dispute, 2) considers new options for dealing with it, and 3) decides on some steps that can be taken. Some of the questions that can be asked to facilitate discussion on each of these topics are listed in Table 3-5.

**3.6.4 Negotiation**

When disputes become polarized and harden into seemingly irreconcilable positions, the group must look for ways to break the stalemate that has developed. Some form of direct negotiation among all the parties in the dispute is often an effective way to solve this problem. Negotiation is a structured session in which bargaining takes place in an effort to reach a satisfactory solution.

In a typical negotiation approach, each side takes a position, argues for it, and then makes concessions to reach a compromise. This type of negotiation is



called positional bargaining and it is generally practiced with either a "soft" or "hard" approach. In the "soft" approach, the negotiator views the participants as friends and the goal is agreement above all else. In the "hard" approach, the negotiator views the partici-

*"Community planning is a huge negotiating process, but sooner or later a decision has to be made. How do you get to the decision?"*

pants as enemies and the goal is victory. These approaches to negotiation can certainly help to resolve some disagreements, but there are many situations where they have severe limitations (Fisher and Ury, 1981).

There is another approach to negotiation that

is not based on positional bargaining, but that seeks to identify mutually satisfying options based on the basic interests that are involved. The most widely known version of this type of negotiation is called "principled negotiation" or "negotiation on the merits." This approach was developed by Roger Fisher and William Ury of the Harvard Negotiation Project and it offers a framework for negotiation that is applicable to a wide range of disputes (Fisher and Ury, 1981).

### 3.6.5 Mediation

The general purpose of mediation is to provide impartial third-party assistance and a structured environment for dealing with a polarized dispute (The Program for Community Problem Solving, 1992). Mediation can be defined as "assisted negotiation." It is de-

**Table 3-4: Possible Approaches to Common Group Disputes**

The following table presents some common group disputes and the approaches most often used to address conflicts of this nature. Multiple approaches are listed on each dispute since conflicts are specific to the situation. In order to determine the most appropriate strategy, members should consider the intensity of the conflict, the willingness and ability of the group to respond, and the possible outcome or consequences of a given approach. Since each conflict and resulting dispute is unique, there may be instances where a strategy that would best address the conflict is not listed here.

Nature of Dispute	Probable Approaches
Members expressing dissatisfaction with interactions during meetings	Process Consultation/Coaching
Differences over data interpretation	Data Exchange Meeting Joint Problem Solving Non-Binding Third Party Recommendations
Questions regarding the structure or process of group meetings	Process Consultation/Coaching Joint Problem Solving
Personal misunderstanding between members	Process Consultation/Coaching Negotiation Mediation
Members supporting different priorities	Negotiation Mediation Ten-Step Mediated Dialogue Non-Binding Third Party Recommendations
Highly polarized positions due to hurt feelings or program disagreements	Mediation Ten-Step Mediated Dialogue
Continued stalemate after attempts at mediation or negotiation	Third-Party Decision Making

signed to operate when relatively high levels of confrontation develop between the parties, and is therefore more structured than most other approaches to dispute resolution.

The mediator's task is to create a context in which the parties involved can come together and search for ways to bridge their differences. A mediator may use principled negotiation in an informal session involving a small number of participants, or may wish to follow a more structured format to include a larger number of participants. In the Ten-Step Mediated Dialogue Model (see example at end of chapter), the mediator is able to work out differences between representatives of opposing factions while engaging the rest of the members to help find possible solutions.

### **Table 3-5: Joint Problem Solving— Questions to Ask**

#### **1. Analyzing the dispute:**

- Where does the problem lie?
- How did the disagreement start?
- What are the assumptions or suspicions that each side has about the other?
- What do each of the parties want?

#### **2. Considering new options:**

- How can new data be obtained to increase understanding?
- What criteria should be used to decide what data to use?
- Is there any way that the parties involved can compromise or split the difference between them?
- What are the real interest of all parties involved?
- What are all the possible ideas for how to approach this problem?

#### **3. Deciding which step(s) to take:**

- Which approach is most helpful to the group's overall task?
- Which option most closely meets the criteria agreed on?
- Which steps are easiest to implement?

One additional feature of mediation is that the mediator can choose to hold some meetings with the involved parties separately. This enables the mediator to learn more information about the dispute through one-on-one interaction with each party.

In mediation, the parties involved control the outcome by their willingness to come to agreement. However, the mediator may also play an active role by suggesting possible areas of agreement or even drafting a working document for a settlement. Thus, the mediator holds a somewhat tighter reign on the process than someone who is facilitating a joint problem solving session.

### **3.6.6 Non-Binding Third-Party Recommendations**

Another way to use an impartial third party is to have them give advice that a group is free to either accept or reject. In this case, the third party would generally be chosen for his or her expertise in a particular content area. If participants in a dispute want to use this approach then they must agree among themselves on the person or persons who will fulfill this role.

This type of approach is generally used when neither help with data nor various approaches to procedural assistance has enabled the parties to break an impasse. The process used in this type of intervention is usually formal and does not allow parties to engage in negotiation. In a semi-judicial forum, the disputants present the facts (as they are perceived by the parties) to the agreed upon third-party advisor. After considering the various arguments and points of view, the advisor makes a recommendation that the parties may or may not use (Jones, 1994).

### **3.6.7 Third-Party Decision-Making**

This is the only approach to dispute resolution mentioned here that actually takes decision-making power away from the parties in a dispute. Groups should consider this approach only in instances in which they are hopelessly deadlocked.

Binding third-party decision-making authorizes an individual expert, or perhaps a panel of experts, to listen to the arguments of the various parties and then to prescribe an outcome or settlement. This type of binding decision-making, or arbitration, is generally used when all previous dispute resolution means have failed or when a group is dealing with specific legal questions or violations.

## Sample Disclosure Form

### The XYZ HIV Health Services Planning Group Conflict of Interest Disclosure Form

The XYZ HIV Health Services Planning Group has members who are professionally or personally affiliated with organizations that have, or may request or receive funds for HIV prevention activities. Because of the potential for conflict of interest, this Disclosure Form has been adopted by the XYZ Planning Group and must be completed by all current and future group members.

By my signature below, I certify that:

(1) I have read, understand and support Section ABC-"Conflict of Interest" of the Planning Group's By-laws.

(2) I and/or a family member am/are (has/have been within the past twelve months) serve(d) in a staff, consultant, officer, board member, or advisor capacity with the following organization(s) that has/have received, may seek or is/are eligible for funding HIV prevention activities.

Organization: \_\_\_\_\_

Title: \_\_\_\_\_ Period of Affiliation: \_\_\_\_\_

Organization: \_\_\_\_\_

Title: \_\_\_\_\_ Period of Affiliation: \_\_\_\_\_

Organization: \_\_\_\_\_

Title: \_\_\_\_\_ Period of Affiliation: \_\_\_\_\_

(Please attach additional pages if necessary)

Group Member: \_\_\_\_\_

Signature: \_\_\_\_\_

Date: \_\_\_\_\_

Date Form Received by the Planning Group: \_\_\_\_\_

## A Ten-Step Mediated Dialogue Model

**Step One:** Identification of a topic that includes the concerns of all parties. Topics of discussion that are slanted in a particular direction or toward a specific point of view make it difficult to reach out to a wide range of participants. The topic for dialogue must be one that includes all the basic problems and goals as they are perceived by people with divergent views.

**Step Two:** Agreement on the goal of the dialogue and the guidelines by which it will be conducted. Participants acknowledge that the purpose of the dialogue is to focus on ways to cooperate and agree to follow certain guidelines that will facilitate that cooperation.

**Step Three:** Statement and definition of the initial positions of the participants. Each of the participants takes a few minutes to define his/her basic views on the topic and to suggest initial positions for consideration by others in the dialogue.

**Step Four:** Restatement of the initial position given by someone of a different point of view. Each participant in the dialogue restates the major points made by a representative of another point of view.

**Step Five:** Questioning by the facilitator and the observing participants that begins to probe for areas of agreement and disagreement. The facilitator and/or any concerned members observing this process asks questions of the dialogue participants in order to begin to identify specific ways that they agree and disagree.

**Step Six:** Identification by participants of areas of agreement and disagreement. The facilitator states the items of agreement that have already been reached and then leads the participants in an exploration of other ways in which they agree and disagree.

**Step Seven:** Examination of the areas of disagreement through a focus on the interests (or goals) behind the different positions. The facilitator turns the dialogue to a consideration of some of the issues where the participants have found disagreement. The facilitator notes where there is agreement on what they are trying to achieve and has participants expand on those areas.

**Step Eight:** Brainstorming led by the facilitator in which participants seek to discover new options for meeting the shared interests they have behind their policy disagreements. One by one the participants look at the agreements they found in Step Seven and list as many different ideas as they can think of about how some aspect of these common interests can be met.

**Step Nine:** Identification of any new ideas (or options) that are agreeable to all participants. The facilitator directs the dialogue to a consideration of new ideas that have emerged that may be acceptable to all parties. Participants are urged to look briefly at many different ideas in an effort to identify as many as possible that are agreeable to all concerned.

**Step Ten:** Discussion by participants of specific ways that they might work together after the conclusion of the dialogue. All points of agreement are summarized and dialogue participants consider specific steps they can take to work together to implement the things on which they have agreed.

(Schindler and Lapid, 1989)

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# Notes From the Field:

## Conflict of Interest and Dispute Resolution

### OVERVIEW

All of the state AIDS directors reported concerns over possible conflict of interest and dispute issues that may arise in relation to community planning. They expressed concerns about preparing health department staff as well as members of the planning groups to anticipate potential areas for disputes and conflict of interest before they occur; to avoid conflict of interest and disputes; and to manage and resolve disputes when they occur.

Several of the respondents provided examples of either conflict of interest or disputes from past community planning experiences. Their experiences seemed to indicate that disputes are more likely to arise among group members when there are power struggles; emotional issues; dual loyalties; basic distrust; lack of consensus over distribution of funds and resources; and difficulties over decision-making.

The states made many recommendations, summarized in the other sections on participatory planning and valuing and managing the planning process, that, if implemented, will foster an effective community planning process and serve to minimize disputes as well. As one respondent said, "Conflict is unavoidable. Let's find out what strategies are useful in managing it."

Some additional suggestions and lessons learned from the states about avoiding conflict of interest, and managing and resolving disputes are provided below.

### AVOIDING CONFLICT OF INTEREST

**C**larify conflict of interest rules and regulations. The respondents who addressed the issue of conflict of interest recommended that the states take a preventive approach by providing planning groups with information and technical assistance on any rules and regulations governing conflict of interest. This will enable groups to recognize and avoid any situations that may constitute a conflict of interest.

### MANAGING DISPUTES

**K**eeep the planning group focused and on target. One planning group reported power struggles when executive directors of community-based organizations were more concerned with their own agenda items, rather than the entire planning process. For current planning activities, this state is committed to keeping the planning group on target, staying focused, and developing a strong plan in hopes of keeping the power struggles to a minimum.

Another state described a power struggle when organizations with different missions and purposes served together on planning committees. In this case three of the four organizations were service providers to persons with HIV. The other organization's main purpose was condom distribution. The differing perspectives created by disparate purposes created a power struggle and conflict.

*Listen to all sides and encourage a balanced perspective.* Many states reported disputes over issues that seemed to generate intense emotions and opinions, especially around decisions involving testing, HIV reporting, partner notification, condom use, and sex education. States also reported disputes over how and which prevention messages get developed. One state suggested that the group has to be committed to balancing out the prevention messages. A respondent stated the importance of "meeting people where they are. Some groups can create barriers, but they are also part of the diversity of the community so we must be able to focus on all kinds of prevention messages."

In one state, the issue of reporting HIV status by name has been very controversial. The state AIDS director anticipates ongoing emotional conflicts over a state law that mandates reporting by name, as well as conflicts around sex education, condom use versus abstinence, and addressing the prevention needs of the community.

*Help the group deal with dual loyalties.* Some states described the conflict that arises when individuals on a planning committee may see issues in their own community as more important than the statewide planning process. The struggle over dual loyalties can create conflict and disputes.

*Encourage open communication and bring important issues to the group's attention.* One respondent indicated that disputes among group members can often occur when communication about issues is not open and honest or when key issues are not brought to the table. This state AIDS director stated, "At times we kept things to ourselves that should have been brought to the attention of the group. This created basic distrust among the group." Sometimes the problem is the failure of group members to recognize when issues are the private concern of individuals versus the legitimate concern of the group. Communicating openly about the issues that are truly at the heart of the dispute enables the group to create trust. It also enables group members to determine which disputes need to be heard and resolved by the group.

According to one state, some conflicts may be interpersonal in nature among group members; others may arise when project staff on the planning committee attempt to solve problems that actually should be dealt with on the executive level. Knowing when an issue or dispute should not be handled by the planning group is also important.

*Be flexible on how to arrive at group decisions.* One respondent described community planning as a negotiating process, but stated that, "Sooner or later a decision must be made. How do you get to the decision?" One state reported that if the group could not come to consensus then the group would go to a vote. If no agreement could be reached on how to proceed, the decision was left up to the State Office of AIDS. But there has to be an enormous amount of trust for this process to work.

Several respondents recommended better guidance for the planning groups on decision-making related to priority setting. Since there are so many factors that can influence decisions about priorities, this is an area that has been a recurring point of conflict during previous planning efforts. One state AIDS director thought that "this is where a lot of people get frustrated and quit the process." He suggested that disputes over decision-making may be prevented or minimized by providing group members with technical assistance in communications and listening skills, group dynamics, and ways to bridge language barriers, cultural gaps, and differing points of view.

### **Prevention Planning Profile**

California's Title II statewide advisory group was authorized to set priorities and to allocate funds for each priority. Making decisions about 28 million dollars was a challenging task with the potential for conflict not only among committee members but also between the planning group and the state health department. The state's commitment to the group was to trust its decisions and to go forward with its recommendations all the way to the governor's office. The group felt empowered and supported by the Office of AIDS. Backing up the decision-makers helped to prevent conflict.

### **Lessons Learned on Avoiding Conflict of Interest and Managing Disputes**

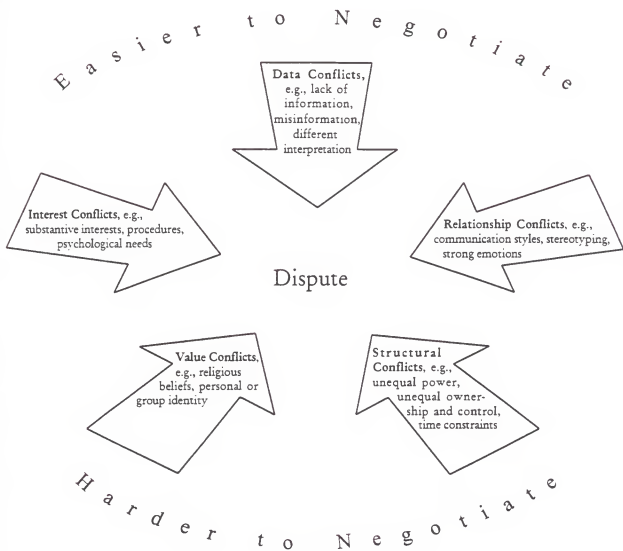
- Provide technical assistance to planning groups on how to avoid conflict of interest and how to manage and resolve disputes.
- Set up a process in advance to handle conflicts.
- Don't make too many autocratic decisions.
- Clarify roles, responsibilities, and group expectations.
- Encourage open, facilitated communication.
- Aim for a balanced perspective.



# Handouts

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## Sources of Group Dispute



This chart was created from material contained in "An Introduction to Negotiation and Conflict Resolution." Institute for Conflict Analysis and Resolution. Fairfax VA; George Mason University, 1994. The material was adapted from concepts developed by Dr. Chris Moore in, *The Mediation Process*. San Francisco: Josey-Bass, 1986.



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## Seven Principles of Dispute Resolution

1. Establish a goal that includes the concerns of all involved.
2. Maintain a climate of fairness and mutual respect.
3. Distinguish between the person and the problem.
4. Identify and build upon areas of agreement.
5. Distinguish between interests and positions.
6. Develop options for mutual gain.
7. Use objective criteria.

# Principles of Geography

Chapter 1: Introduction to Geography

Section 1.1: The Nature of Geography

Section 1.2: The Scope of Geography

Section 1.3: The Importance of Geography

Section 1.4: The History of Geography

Section 1.5: The Future of Geography

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## Conflict Checklist

This checklist is designed for highlighting key steps to take when a conflict has escalated into a dispute.

### 1. Look for the sources of the conflict

- ☐ financial interests
- ☐ data
- ☐ relationship
- ☐ interest
- ☐ structural
- ☐ value
- ☐ cultural differences in addressing conflict

### 2. Evaluate the group's ability to respond

- ☐ determine characteristic response styles to conflict
- ☐ assess the climate of the group: communication skills and ability to bridge differences

### 3. Analyze the dispute situation

- ☐ number of people involved
- ☐ state of working relationships
- ☐ ability of members to be objective
- ☐ intensity of the problem; the balance between reason and emotion
- ☐ how long the problem has persisted
- ☐ consequences for all parties
- ☐ level of agreement beyond the apparent disagreement
- ☐ existence of objective criteria for addressing dispute

### 4. Develop a win/win solution

- ☐ establish a common goal
- ☐ maintain fair climate of mutual respect
- ☐ distinguish between people and the problem
- ☐ identify and build on areas of agreement
- ☐ focus on interests behind positions
- ☐ use objective criteria
- ☐ explore options for mutual gain

### 5. Determine appropriate strategy

- ☐ process consultation and coaching
  - ☐ data exchange meeting
  - ☐ joint problem solving
  - ☐ negotiation
  - ☐ mediation
  - ☐ Ten-Step mediated dialogue
  - ☐ non-binding third-party recommendations
  - ☐ third-party decision-making
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## Chapter 4

# Developing an Epidemiologic Profile

4.1 Overview	4-1
4.2 Inventory of HIV/AIDS Data Sources for Prevention Planning	4-5

The Community Planning Process	Community Planning Tasks	Additional Resources
1. Ensuring Community Participation 2. Valuing and Managing the Community Planning Process 3. Conflict of Interest and Dispute Resolution	4. Developing an Epidemiologic Profile 5. Assessing and Setting Priorities for Community Needs 6. Setting Prevention Program Priorities 7. Selecting Among HIV Prevention Interventions: Theoretical Basis, Effectiveness, and Cost-Effectiveness 8. Evaluating the Community Planning Process	9. Resources for HIV Prevention Community Planning



# Chapter 4

## Developing an Epidemiologic Profile

### 4.1 OVERVIEW

In order to accurately target HIV prevention activities, a planning group should have community-wide information on the number and characteristics of persons becoming newly infected with HIV each year, as well as reliable estimates of likely future trends. In addition to information on HIV infections, community planners should know the number and characteristics of persons whose behaviors or other exposures put them at various levels of risk for HIV infection. However, it is impossible to obtain such data at a cost or level of personal intrusiveness that would be acceptable to any community. Thus, a variety of other less direct or less comprehensive measures must be used. The use and interpretation of these various data sources requires epidemiologic judgment in assessing their strengths and limitations as they are pieced together to develop a community profile. The expertise of community representatives will be essential in filling the gaps in the data and assessing the data in the context of local prevention needs, based on their first-hand familiarity with groups at risk for, or infected with, HIV.

There are a number of different types of epidemiologic data that a planning group can examine in order to develop a useful community profile. Public health surveillance systems, which represent ongoing data collection, analysis, and dissemination activities by public health agencies at local, state, and national levels are widely available. In a number of areas, more focused research projects may also be available to provide information that may be useful to local community planners. At a minimum, all communities should have access to locally collected data on AIDS cases, vital statistics data on HIV-related mortality, HIV seroprevalence data from several population groups, and data that represent surrogate markers for HIV-risk behaviors, such as STD rates. The

### Definitions

**Epidemiology**—The study of the patterns and determinants of health and disease in populations. Epidemiology is the science that underlies the public health practice of disease prevention and control. Epidemiologists seek to define the occurrence of disease in terms of:

- *when* are diseases occurring, what are the trends?
- *where* are diseases occurring, where are events occurring that place individuals at risk for disease?
- *who* is affected, what is the pattern of disease in affected persons, what groups are at greatest risk?
- *what* are the exposures or behaviors that place individuals at risk for disease?

**Incidence**—The number of new cases of a disease or condition that occur within a given time period. Often incidence is expressed annually, e.g., the number of new cases occurring during a year.

**Prevalence**—The number of persons living with a disease or condition during a given time period.

**Incidence and prevalence rates**—The number of incident or prevalent cases per a standard population size, often expressed as cases per 100,000 population.

**Public health surveillance**—An ongoing process of information collection, analysis, interpretation, and dissemination to monitor the occurrence of specific health problems in populations. Surveillance is used to guide and evaluate public health policy and programs.

discussion below provides an overview of the major categories of data that should be available to and reviewed by all community planning groups. Section 4.2 then provides a more detailed description of the strengths and limitations of specific data sources likely to be available to all areas, many areas, and just a few areas. The types of information available to different areas will vary. Those with more information will be able to develop a more detailed profile of the HIV epidemic in their communities. But "more data" is not a prerequisite to developing a useful epidemiologic profile. A desire to collect more information should not distract from efforts to make the best use of information that is locally available.

It is important to keep in mind that the information from the various monitoring systems described in this document will provide a starting point but not definitive guidance for the deliberations of the community planning groups. For example, even if accurate, complete, and up-to-date information were available regarding the characteristics of persons with recently acquired infections, it may be necessary to judge how preventive resources should be balanced between

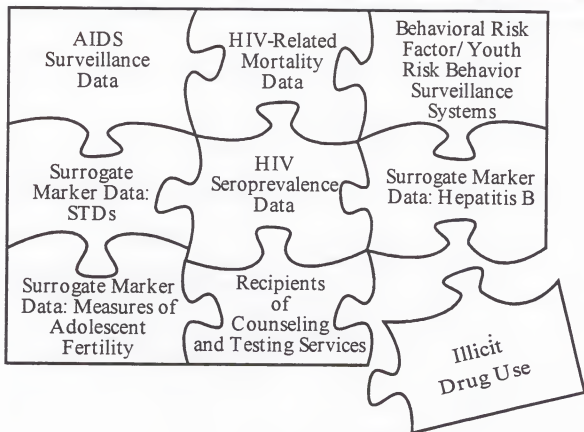
those who account for current infections and those likely to account for future infections. Similarly, these data may be useful in assisting planning groups to identify populations in need of preventive services, but they are not likely to be useful in defining which types of interventions will be effective among specific groups.

#### 4.1.1 Overview of Categories of Widely Available HIV Prevention Planning Data

Because no one epidemiologic data set will provide a complete picture of HIV/AIDS in the community, planning groups should assemble data from several categories. As this graphic shows, data from a variety of categories can provide a more complete picture of past and present infections and point out likely trends in future infections. These data categories are described in greater detail below.

4.1.1.1 AIDS Surveillance Data. AIDS case reports represent persons in the later stages of HIV infection. Because of the long period between HIV infection and

#### Widely Available HIV-Related Epidemiologic Data



the occurrence of AIDS-defining conditions (on average about 10 years), AIDS cases do not necessarily represent the characteristics of persons with more recently acquired infections. However, changes in the characteristics of HIV-infected persons are mirrored by changes in AIDS trends. For example, greater relative increases in AIDS cases among women in recent years indicate that a greater percent of new HIV infections are occurring among women as compared with earlier years. In addition, AIDS case data are the *only* HIV data consistently available on a population-wide basis in all states by sex, race/ethnicity, age, and mode of HIV exposure. Thus, an important step in developing a community profile would be to describe trends in AIDS cases, to describe recently reported cases, and to note any recent changes that have occurred in the characteristics of persons with AIDS.

AIDS data have also been used to estimate the number of HIV-infected persons, trends in HIV incidence, and to project short-term future trends in AIDS cases. Such estimates are based on a mathematical technique (back calculation) that depends on estimates of the duration between infection and disease, on the effect of treatments in delaying AIDS onset, and of the number of people receiving treatments. They are most useful in projecting AIDS trends and least useful for estimating recent trends in HIV incidence. These mathematical techniques require "large numbers," meaning that they can be applied only in the largest communities, limiting their use in local areas and for projecting trends among population subgroups. The use of the back calculation method is complicated by changes in AIDS surveillance criteria. For all of these reasons, such projections require sophisticated statistical expertise. More crude estimates for local areas can be made, however, by extrapolating from national estimates. Thus, for example, if a given area accounts for X percent of national AIDS cases, that percent can be applied to national AIDS projections and to the national estimate of infected persons. This technique will underestimate future AIDS trends and the number of infected persons in areas where AIDS cases are increasing more rapidly than national trends, and vice versa.

**4.1.1.2 HIV-Related Mortality Data.** Mortality data are useful in communicating the impact of HIV infection. Concepts such as "leading causes of death" and the percent of all deaths attributed to HIV infection are readily understood by general audiences. Mortality data are independent of definitions used for AIDS

reporting because they represent deaths attributed to *HIV infection*.

HIV-related mortality data should be examined for specific age groups, since the impact of HIV is highly age-specific. Often, the age group of 25-44 years is used, since this corresponds with standard categories used by National Center for Health Services (NCHS) in reporting mortality and with the age of most persons dying from HIV infection. For example, HIV infection is now the leading cause of death among men 25-44 years of age and the fourth leading cause among women 25-44 years of age, accounting for 20% and 7%, respectively, of deaths among men and women in this age group in the United States.

Trends in HIV-related mortality, particularly when shown graphically, provide an especially potent indication of the impact of HIV, when compared with other leading causes of death, which have been relatively stable. While vital statistics data are likely to be important in drawing attention to the impact of HIV in a community, their usefulness for community planning is limited, since they do not provide information on modes of HIV transmission. Also, mortality data underestimate the impact of HIV in communities or groups more recently affected by HIV.

**4.1.1.3 HIV Seroprevalence Data.** HIV seroprevalence surveys measure the level of HIV infection among selected populations that have been targeted for surveys. These range from individuals who as a group are not at particularly high risk for HIV infection (e.g., blood donors, childbearing women, military recruits) to persons at a relatively high level of risk for HIV infection (e.g., persons attending STD or drug treatment centers).

Virtually all states should have access to data on HIV prevalence among childbearing women, military recruits, Job Corps applicants, and blood donors. In addition, a number of seroprevalence surveys have been conducted in a variety of clinic-based settings in different cities. Among these surveys, the one in childbearing women is the only population-based survey, meaning that it represents virtually all women delivering live-born children within a defined geographic area. All the other surveys are based on "sentinel" populations, meaning that the observed seroprevalence levels represent HIV infections in selected groups, but they may not represent the seroprevalence in all comparable individuals. For example, the HIV seroprevalence in persons attending two STD clinics within a city may or may not be truly representative

of all persons with STDs in that city. Likewise, illicit drug users in selected drug treatment centers may or may not be representative of all drug users, including those in and out of treatment.

The greatest power of these data is in documenting the extent and potential impact of HIV that is not yet manifest as severe disease. As such, these data have been extremely useful in demonstrating to communities that HIV is indeed a larger problem than many had previously assumed.

**4.1.1.4 Behavioral Risk Factor Surveillance System (BRFSS) and the Youth Risk Behavior Surveillance System (YRBSS).** The BRFSS is a telephone-based survey conducted by nearly all states and provides information on a variety of health risk behaviors and knowledge, ranging from cigarette smoking to alcohol and drug use to seat belt use to HIV-related knowledge. Questions about HIV focus on the respondent's understanding of how HIV is transmitted, how transmission can be prevented, and on self-perceived risk of infection. The YRBSS includes national, state, and local school-based surveys of adolescents, and similarly addresses a range of health-related issues, including drug use and sexual behavior. These surveys are aimed at the general population of residents in a state (BRFSS) or the general population of adolescents in school (YRBSS) and provide general, rather than highly specific, information about HIV-related knowledge (BRFSS) and risk behaviors (YRBSS). Thus, they are likely to be most useful in planning community-wide education programs and less useful in targeting specific high-risk groups.

**4.1.1.5 Surrogate Markers of HIV Risk Behaviors.** Syphilis and gonorrhea are reportable diseases in all states; reporting requirements for other STDs vary among states. Reporting levels are generally less complete compared with reporting of AIDS cases, and reporting is likely to be most complete among persons receiving STD services in the public sector. Because STDs result from unsafe sexual behaviors, their occurrence is a reflection of the level of unsafe sexual activity resulting in disease transmission in a community. Syphilis rates are probably a better reflection of HIV risk than gonorrhea rates. While STD rates provide a measure of unsafe sexual behaviors, they do not necessarily correlate with HIV risk, which depends both on the level of unsafe sexual activity and the level of HIV infection among networks of sexually active people. In some areas, STD rates may correlate strongly with HIV risks; in other areas they are more

likely a measure of the potential for HIV transmission.

Trends in STD rates may provide a good indication of dynamic changes in the community that directly affect HIV transmission. For example, declines in rectal gonorrhea rates among men during the 1980's were viewed as a reflection of changing sexual norms in the gay community (although those changes have not been uniform or uniformly sustained as demonstrated by information from more recent surveys). Increases in syphilis in tandem with the crack cocaine epidemic demonstrated the potential for increased heterosexual transmission of HIV in the "crack house" milieu. However, trends in syphilis cases within local areas may reflect the status of local syphilis epidemics, and increases or decreases in syphilis rates may not correlate with variations in HIV risk.

Like HIV, hepatitis B is transmitted by sexual contact, through exposure to blood, perinatally; and it is a reportable disease in nearly all states. Hepatitis B case reports may also provide information on exposure risks (e.g., male-to-male sexual contact, illicit drug injection). Thus, trends in hepatitis B cases may reflect changes in behavior associated with HIV risk. However, in many areas, hepatitis B reporting is passive (e.g., health department staff do not actively solicit case reports from care providers), and thus completeness of reporting is less than for AIDS cases.

Other markers of sexual activity are less direct measures of HIV risk. For example, measures of adolescent fertility (abortion and birth rates) can estimate the level of unprotected intercourse among heterosexual teenagers. However, these measures do not necessarily predict the risk of disease transmission. Adolescent abortions suggest pregnancies that were not intended.

**4.1.1.6 Other Data Sources.** Information on persons who receive HIV counseling and testing services, including the number of positive tests, should be available from local counseling and testing services. These data can provide information on the number of HIV tests that are conducted at these sites, the characteristics of persons who use these services, and the percentage of tests that are positive. Based on interviews of persons reported with AIDS cases, these sites account for less than a third of HIV diagnoses (other common sites include hospitals and private physician offices).

Information on illicit drug use may be available from state alcohol and drug agencies. This may include estimates of the number of drug injectors, the

number of treatment positions available and the length of waiting lists, and patterns of illicit drug use obtained from the Drug Abuse Warning Network (DAWN).

In preparing for the community planning process, each health department will need to assess the availability of information on HIV/AIDS and risk behaviors for its jurisdiction and to assemble this information into a package that will be useful to the community planning group. This includes the use of data from public health surveillance systems described in this document and data from other sources that may be available from local research projects. The strengths and limitations of these data as measures of risk behaviors and as a correlate of HIV infection must be assessed.

## 4.2 INVENTORY OF HIV/AIDS DATA SOURCES FOR PREVENTION PLANNING

This section is organized by the level of availability of the data: information collected by all or nearly all states; information collected by many states; and information collected by selected states. In most instances, these data sets are supported by the Centers for Disease Control and Prevention (CDC) through cooperative agreements, which includes funding as well as technical support for data management systems that enable local tabulation. Thus, for the most part, these data should be available from county or state health departments. Table 4-1 summarizes these data sources.

Policies for the release of these data are guided by the importance of maintaining their confidentiality. In addition to strict proscriptions against releasing names (or other identifying information) of persons with HIV infection or persons who engage in what may be illegal behaviors, tabulations should not be made when the number of persons in a reported category (e.g., by geographic area, age, race/ethnicity) is so small that an individual could be identified. As a result, the desire for community planning groups to have highly detailed data must be balanced by the overriding need to maintain confidentiality.

In addition to the surveillance systems described here, there are a number of national surveys that provide data on HIV-related knowledge, attitudes, and behaviors and inpatient and outpatient morbidity. However, because these systems cannot be used to provide state- or county-level data, they will be less useful to community planners.

### 4.2.1 HIV/AIDS Data Available to All (Or Nearly All) Areas

**4.2.1.1 AIDS Surveillance.** AIDS is a reportable condition in all states and territories; all states and areas conduct AIDS surveillance using the 1993 CDC surveillance definition.

*Stated Objectives and Overview:* The AIDS surveillance system 1) monitors the incidence and demographic profile of AIDS; 2) describes the modes of HIV transmission among persons with AIDS; 3) guides the development and implementation of public health intervention and prevention programs; 4) assists in evaluating the efficacy of public health interventions.

Supported in part with funds from CDC, state and local health departments conduct active surveillance for cases of AIDS meeting the CDC surveillance definition. State and local health departments solicit disease reports from health-care providers, laboratories, or other sources, by routinely contacting individual providers and institutions representing likely sources of disease reports. Standardized case report forms and software known as the HIV/AIDS Reporting System (HARS) are used to produce local tabulations and to report AIDS cases (without names) monthly to CDC. Health departments conduct follow-up investigations on persons reported with AIDS who do not report a mode of exposure to HIV. In addition, selected states are collaborating with CDC on special projects to evaluate and improve the accuracy of reported information on modes of HIV exposure, to characterize persons infected with both HIV and tuberculosis, and to evaluate the impact of the 1993 AIDS surveillance definition on reporting of AIDS-defining opportunistic infections.

*Target Population:* All persons meeting the 1993 CDC AIDS surveillance case definition.

*Funded sites:* All state health departments, the U.S. territories, and 6 local health departments (New York City, Philadelphia, Chicago, Houston, San Francisco, Los Angeles).

*Strengths:* The AIDS surveillance system is the principal source of knowledge regarding trends in the number and characteristics of HIV-infected persons. This is the only surveillance system available to planning groups that has a community or state-wide perspective, that includes persons in all age, gender, race/ethnic, and mode-of-HIV-exposure groups, and that pro-

**Table 4-1: Sources and Types of HIV/AIDS Data for Prevention Planning**

Measures of HIV Infection and Morbidity	Measures of Risk Behavior	Measures of Program Services
Widely Available Data		
<ul style="list-style-type: none"><li>• AIDS surveillance</li><li>• Vital statistics</li><li>• National HIV Survey of Childbearing Women</li><li>• Blood collection centers, HIV prevalence in blood donors</li><li>• HIV screening of Job Corps entrants</li><li>• HIV screening of civilian applicants for military service</li><li>• Surveillance of occupationally acquired HIV infection</li></ul>	<ul style="list-style-type: none"><li>• Behavioral Risk Factor Surveillance System</li><li>• Youth Risk Behavior Surveillance System</li><li>• Surveillance of Bacterial Sexually Transmitted Diseases</li><li>• Surveillance of Occupationally Acquired HIV Infection</li></ul>	<ul style="list-style-type: none"><li>• Data from HIV counseling and testing programs</li></ul>
Data Available to Many States		
<ul style="list-style-type: none"><li>• HIV infection surveillance</li><li>• HIV-related hospitalizations</li></ul>		
Data Available to Selected Areas		
<ul style="list-style-type: none"><li>• HIV sentinel hospitals survey</li><li>• Clinic-based HIV serologic surveys</li><li>• The National Death Index (NDI) project</li><li>• Pediatric Spectrum of Disease Project</li><li>• The Adult and Adolescent Spectrum of Disease Project</li></ul>	<ul style="list-style-type: none"><li>• Clinic-based surveys of risk behaviors</li><li>• Supplement to HIV/AIDS Surveillance (SHAS) Project</li></ul>	
National Systems That Do Not Provide Local Data		
	<ul style="list-style-type: none"><li>• National Survey of Family Growth (NSFG)*</li><li>• National Health Interview Survey (NHIS)*</li><li>• National Household Survey of Drug Abuse†</li><li>• National Health and Social Life Survey†</li><li>• National AIDS Behaviors Survey†</li></ul>	<ul style="list-style-type: none"><li>* CDC supported</li><li>† non-CDC supported</li></ul>



vides a historical perspective in trends dating to the earliest recognition of the AIDS epidemic. While AIDS cases reflect HIV infections that occurred in earlier years, monitoring trends in AIDS cases has been instrumental in drawing attention to emerging patterns in the HIV epidemic. Completeness of reporting of AIDS cases (determined using the 1987 surveillance definition) is estimated to be 80%-90%. In 1993, the AIDS surveillance definition was expanded to more accurately reflect the full spectrum of HIV-related immunosuppression and morbidity. Health departments have a well-established record of protecting the confidentiality of AIDS case reports from unauthorized or inappropriate disclosure or use.

AIDS surveillance data provide the basis for mathematical models that are used to estimate HIV incidence and prevalence and to predict short-term future AIDS incidence. These mathematical models employ a technique called "back calculation," which estimates the number and trends in HIV infections that must have occurred in order to yield observed AIDS cases. This technique has been used nationally and in a limited number of large areas, e.g. San Francisco, Los Angeles, and Washington DC. Past predictions using this method have generally been consistent with subsequently observed AIDS trends.

*Limitations:* Because of the long and variable period from infection to development of AIDS, trends in AIDS case data do not represent recent HIV infections or all HIV-infected persons. AIDS surveillance data do not represent persons whose HIV infection is not recognized or diagnosed.

With the 1993 expansion of the AIDS surveillance case definition, reporting may be less complete because of incomplete HIV and CD4+ T-lymphocyte testing among infected persons. The expansion of the surveillance definition will temporarily disrupt interpretation of trends in the number of AIDS cases. An evaluation of surveillance activities will be necessary to assess the effects of these factors on disease reporting.

Current mathematical techniques for estimating HIV prevalence and incidence using AIDS data are imprecise and can only be applied nationally or in large areas with the highest AIDS incidence. These techniques are complex and require sophisticated statistical expertise.

**4.2.1.2 Vital Statistics.** All states maintain registries of deaths. Assessing the number and rate of HIV-related deaths provides a simple measure of the impact

of HIV in a community, particularly when death rates are examined by age group.

*Stated Objectives and Overview:* The primary objectives are to enumerate and characterize mortality attributed to HIV infection using vital statistics. These data are coded from death certificates collected by state vital registrars. These data have been used to characterize the impact of HIV infection on mortality, to assess the completeness of AIDS case reporting, and to compare trends in HIV infection mortality with trends for other leading causes of death. These data have also been useful in increasing awareness of the problem of HIV infection.

*Target Population:* All deaths occurring within the 50 States, the District of Columbia, and U.S. territories.

*Strengths:* These are state-wide databases representing all deaths occurring among state residents. Based on a legal document (i.e., the death certificate), filing is nearly 100% complete.

*Limitations:* Data on causes of death are based on information recorded by the certifying physician. Recorded information may be inaccurate or incomplete. Because of underreporting of certain causes of death, the number of HIV-related deaths and the spectrum of related conditions will be underestimated to some extent. Vital statistics data are not as timely as AIDS case reports.

**4.2.1.3 National HIV Survey of Childbearing Women.** The Survey of Childbearing Women is part of a broad system of monitoring the prevalence of infection among selected populations using "unlinked testing." This means that left-over blood specimens routinely collected for other purposes are anonymously tested for HIV infection after all personally identifying information is removed.

*Stated Objectives and Overview:* This survey estimates the prevalence of HIV infection among childbearing women. The survey is based on unlinked testing for HIV antibody using specimens that are left-over after routine newborn metabolic screening. A positive test reflects HIV infection in the mother, although not necessarily in the infant because maternal antibodies cross the placenta during pregnancy.

*Target Population:* This survey is conducted in 44 states, the District of Columbia, Puerto Rico, and the U.S. Virgin Islands. Between 1988-1992, more than 8 mil-

lion dried blood spot specimens were tested for maternal HIV antibody in state public health laboratories, representing about one-third of all live births during that period.

*Strengths:* HIV seroprevalence rates, unbiased by patient self-selection, are obtained in this population-based survey of national scope. "Population-based" means that the survey is representative of all women who deliver live-born infants and it is not limited to women delivering at selected facilities. The survey also indirectly measures incidence of HIV infection in newborns.

*Limitations:* This system does not collect HIV risk behavior data on childbearing women. It does not represent women who do not deliver live-born infants.

#### 4.2.1.4 Blood Collection Centers, HIV Prevalence in Blood Donors. All blood donated for transfusion is screened for HIV.

*Stated Objectives and Overview:* Data from blood banks are widely available regarding the level of HIV infection among blood donors. In addition, CDC collaborates with the American National Red Cross and major blood collection centers to evaluate donation incentives and risk patterns of HIV-infected donors through detailed interviews and follow-up. These data from individual areas can be compared with patterns observed nationally.

*Target Population:* Approximately 8 million people donate about 13 million units of blood annually in the United States, making blood donors the largest group in the United States that tested is for HIV.

*Strengths:* Given the size of the blood donor population and the fact that persons in the traditional risk behavior groups are deferred from donating blood, new or emerging patterns of HIV transmission (e.g., heterosexual transmission), may be reflected by a change in HIV-risk profile and seroprevalence rates among blood donors. The blood donor study conducted in selected areas provides a means to evaluate donor deferral strategies and to learn more of the determinants of donation behavior among seropositive donors.

*Limitations:* This serosurveillance system targets a population with HIV prevalence rates that are lower than those of the general population because of donor deferral policies.

4.2.1.5 HIV Screening of Job Corps Entrants. The Job Corps screens applicants for HIV infection. Data from this program can be used to assess the extent of HIV infection among disadvantaged youth. Aggregate data (without names) are available from the Job Corps for applicants from local areas.

*Stated Objectives and Overview:* The Job Corps is a residential occupational training program for urban and rural disadvantaged youth ages 16 to 21 years. Since 1987, approximately 60,000 Job Corps entrants have been screened each year for HIV. This training program is administered by the U.S. Department of Labor at 106 sites throughout the country. The Job Corps program has no exclusions based on sexual orientation, hemophilia, or past use of drugs; however, current drug addiction is an excludable condition. Job Corps serologic data are used to assess the seroprevalence and trends of HIV infection among economically and educationally disadvantaged adolescents and young adults in the United States.

*Target Population:* Economically and educationally disadvantaged adolescents and young adults ages 16 to 21.

*Strengths:* This is the only national HIV screening program for adolescents and young adults who are not excluded based on sexual orientation or history of drug use. With specific limitations, inferences from Job Corps screening data to the population of economically and educationally disadvantaged youth can be made (e.g., estimating the number of HIV-infected disadvantaged and out-of-school youth). Job Corps screening data also provide information on the relationship between low socioeconomic status and HIV infection.

*Limitations:* Adolescents and young adults who continue to use injecting drugs, who are incarcerated, or who are involved in prostitution or other illegal activities are excluded from the Job Corps. As a result of this exclusion, Job Corps screening seroprevalence are most likely underestimates of the prevalence of HIV infection among youth at highest risk. Job Corps screening data do not include student risk factor information, limiting the ability to detect changes in enrollment patterns and analyze trends in seroprevalence.

4.2.1.6 HIV Screening of Civilian Applicants for Military Service. All applicants for military service are screened for HIV infection. Aggregate data (without names) are available from CDC for each state.

*Stated Objectives and Overview:* Since October of 1985, all persons applying for active duty or reserve military service, the service academies, and the Reserve Officer Training Corps (ROTC) have been screened for HIV infection as part of their entrance medical evaluation. Military applicants have been interviewed by recruiting officials about drug use and homosexual activity—both of which have been grounds for exclusion from military service—before referral for medical evaluation. CDC receives statistical data on a quarterly basis from the Department of Defense in order to describe trends in seroprevalence among adolescents and adults who apply for military service.

*Target Population:* Civilian applicants for military service—primarily between the ages of 17 and 29.

*Strengths:* Given the size of the population tested, new or emerging patterns of HIV transmission (e.g., heterosexual transmission) may be reflected by an increase in seroprevalence rates among applicants for military service.

*Limitations:* As illicit drug use and homosexual behaviors have been grounds for exclusion from military service, seroprevalence rates among applicants for military service underestimate the actual seroprevalence in the general population.

**4.2.1.7 Surveillance of Occupationally Acquired HIV Infection.** Occupationally-acquired HIV infections are rare. However, concerns of health care workers regarding the risk of HIV infection must be addressed.

*Stated Objectives and Overview:* The primary objectives are to determine the number of persons infected with HIV resulting from occupational exposure and to characterize the incidents resulting in transmission. State and local health departments voluntarily participate. Potential cases are identified from possible occupationally related HIV infections reported to state and local health departments. Data collection includes 1) circumstances of exposure; 2) occupation of worker; 3) status of source patients; 4) other risk factors; 5) prophylaxis after exposure; 6) worker demographics; and 7) documentation of sero-conversion.

*Targeted Population:* HIV-infected persons, primarily health care workers (HCWs), who may have acquired HIV through occupational exposure.

*Strengths:* This surveillance system establishes a standardized reporting system for HIV-infected HCWs who fulfill neither surveillance criteria for AIDS nor the enrollment criteria for prospective needlestick studies. This reporting system provides a unique opportunity to address the concerns of HCWs. Data collected from this reporting system will continue to be useful in evaluating transmission of HIV in health-care and public-safety settings and in formulating more effective control and prevention strategies.

*Limitations:* Completeness of reporting is limited for several reasons. HIV infection (in the absence of AIDS) is not reportable in all states, and some states may not have an established system for detecting persons with occupationally-acquired HIV infection. Participation is voluntary on the part of the HCW and on the part of the health departments. Not all persons with occupationally-acquired HIV infection are reported because not all HCWs are evaluated for HIV infection following exposures. Lastly, some HIV-infected workers choose not to participate.

**4.2.1.8 Behavioral Risk Factor Surveillance System.** Forty-nine state health departments conduct general population telephone surveys that address a range of health topics. These surveys can be used to obtain state-level data on HIV-related knowledge, attitudes, and behaviors.

*Stated Objectives and Overview:* The goal of the Behavioral Risk Factor Surveillance System (BRFSS) is to provide uniform chronic-disease-related behavioral data to guide health promotion and disease prevention programs. The system has been in operation for a decade. The BRFSS is a large-scale telephone-based survey that is now carried out in 49 states and Washington DC. The sampling method selects one randomly chosen person within a household for interview. The BRFSS collects data on the major behavioral risk factors for the leading causes of morbidity and premature mortality; HIV-related issues have been incorporated in the survey and make up about one fifth of the core questions. These include questions regarding attitudes about persons with HIV infection, knowledge about the effectiveness of condoms in preventing HIV infection, knowledge about the availability of treatments for HIV infection, self-perception of risk of HIV exposure, and use of HIV testing.

*Target Population:* All adults, ages 18 years and older,

residing in households with telephones. Sample size is roughly 2,000 interviews per year per state.

**Strengths:** The BRFSS is a state-based survey and provides data for state-by-state comparisons. Time trend analyses are possible. The questionnaire can be modified annually to meet state needs. Data turnaround time is relatively rapid for a large survey. States and local areas may add their own HIV-related modules and questions. State BRFSS capacity allows for point-in-time topical surveys.

**Limitations:** BRFSS does not represent households without telephones. The telephone questionnaire is limited to a shorter time than conventional face-to-face surveys. Because BRFSS addresses a variety of health problems, limited time is available for questions about HIV. At present, specific questions about HIV-related behaviors are not included in the BRFSS. As a general population based survey, the BRFSS is not targeted toward those at highest risk for HIV infection.

#### 4.2.1.9 Youth Risk Behavior Surveillance System.

This surveillance system consists of school and household-based surveys of adolescents ages 12-21 across a broad range of health risk behaviors.

**Stated Objectives and Overview:** 1) To focus attention on specific behaviors among youth that cause the most important health problems; 2) to assess whether those behaviors are increasing, decreasing, or remaining the same; 3) to provide data that are comparable among national, state, and local samples of youth.

The Youth Risk Behavior Surveillance System (YRBSS) was developed to monitor priority health-risk behaviors that contribute to the leading causes of mortality, morbidity, and social problems among youth and adults in the United States. The YRBSS monitors six categories of behaviors: 1) behaviors that contribute to unintentional and intentional injuries; 2) tobacco use; 3) alcohol and other drug use; 4) sexual behaviors that contribute to unintended pregnancy and sexually transmitted disease, including HIV infection; 5) dietary behaviors; and 6) physical activity.

Questions about HIV address exposure to HIV education, sexual activity (age at onset, number of partners, condom use, preceding drug or alcohol use), contraceptive use, and pregnancy.

**Target Population:** The YRBSS consists of national, state, and local school-based surveys of representative samples of 9th- through 12th-grade students, college students, and a national household-based survey of 12

through 21 year-olds. In 1993, 43 states and territories and 13 large cities conducted the YRBSS.

**Strengths:** Youth risk behavior surveys are being conducted every odd year by HIV program directors in state and local education agencies throughout the country as part of their cooperative agreements with CDC. The YRBSS questionnaire and protocol can be adapted to meet state and local needs. The YRBSS questionnaire has been modified for college populations and will be modified for other special populations over time. The YRBSS provides information from representative samples of students in public and private schools in urban, suburban, and rural areas, of both sexes, and of different racial/ethnic groups, as well as in-school and out-of-school youth. Results from the state and local surveys are returned to each site within 6 to 8 weeks of submission of data to CDC. National school-based survey results are published within a year of completion of data collection.

**Limitations:** Not all funded states and cities participate. Not all participating states and cities have been able to use all of the core questions. Not all participating states and cities are successful in implementing recommended sampling and administration procedures. As a general survey, space for HIV questions is limited. At present, there are no questions about homosexual behavior.

**4.2.1.10 Surveillance of Bacterial Sexually Transmitted Diseases.** A sexually transmitted infection other than HIV infection represents a visible and immediate health problem that stems from unprotected intercourse with an infected partner. Sexually transmitted disease (STD) patterns in a community represent markers of unsafe sexual behavior that may predict the likelihood and rate of future spread of HIV infection as networks of sexually active people acquire HIV infection. Information from STD surveillance systems can be used to describe sub-populations and geographic areas in which unsafe sexual behaviors occur in order to target primary and secondary HIV prevention activities.

All states and most large city and county health departments have full-time STD prevention programs that support walk-in diagnostic and treatment services and community-wide active case detection services through screening and partner notification activities. All states, territories, and some local jurisdictions receive federal funds from CDC to supplement state and local STD prevention efforts. Many state and lo-

cal programs are extending their potential impact through formal alliances with public and private providers who provide STD services in sites such as reproductive health centers, prenatal clinics, adolescent and student health clinics, community health centers, substance abuse clinics, and correctional institutions.

*Stated Objectives and Overview:* Gonorrhea and syphilis incidence data are used by programs to monitor local and state trends, identify high-risk groups, allocate resources, and monitor program effectiveness.

Gonorrhea and syphilis are reportable diseases in all states. All states require a morbidity report from providers when they diagnose or treat a patient with gonorrhea or syphilis. Most states also require reports from laboratories when a laboratory test suggests direct or indirect evidence of acute or untreated sexually transmitted infection. Provider and laboratory reports are processed by local health departments where morbidity data are recorded and also passed on to the state level. Periodically, states send aggregate STD morbidity reports or summary reports without personal identifiers to CDC where national data are analyzed.

Chlamydia is a widely prevalent STD and state and local programs are in the early stages of organizing chlamydia prevention programs. Approximately 42 states require reporting of chlamydial infection. Chlamydia surveillance is in the developmental stages in the U.S. and accurate trend data are available only in selected areas. Planning groups are encouraged to use these data when they are available in local areas.

*Target Population:* All persons diagnosed with gonorrhea, chlamydia, or syphilis in the U.S.

*Strengths:* Gonorrhea and syphilis data are widely available at the local level and can help describe specific populations in a community where most of the individuals are not HIV infected but who are at considerable risk because of their sexual behaviors and their acute disease status. Considering the relatively short incubation periods for these infections, gonorrhea and syphilis morbidity represent recent consequences of unsafe sexual behavior and point to populations who are potentially at very high risk for acquiring and transmitting HIV infection. Sufficient evidence has accumulated to suggest that the presence of genital ulceration or acute infection of the urethra or cervix actually facilitates the spread of HIV infection when the virus is present. Therefore, identifying and treating persons with acute STDs is an important strategy to

consider when communities wish to lower the probability that an infected individual will transmit HIV infection or that an uninfected person will acquire it. Rapid, steady changes (increases or decreases) in STD rates are often a sensitive sign of changing community norms or the introduction of new transmission co-factors in the community.

*Limitations:* STDs are underreported in all areas. The degree of underreporting varies from community to community. In general, reporting is considered more complete from public clinics and laboratories than from their private-sector counterparts. Therefore, STD community profiles are more likely to reflect the characteristics of persons who receive care at publicly-funded facilities. Missing age, gender, race/ethnicity, and geographic descriptors on local case reports often result in underestimating the impact of disease in the community and limit the ability of analysts to distinguish and target specific subpopulations and their neighborhoods for prevention services.

**4.2.1.11 Data from HIV Counseling and Testing Programs.** All states and territories (and some local jurisdictions) have entered into cooperative agreements with, and receive funds from, CDC to provide a variety of HIV/AIDS prevention services in their areas. Part of these funds are used to support HIV counseling and testing services.

*Stated Objectives and Overview:* The HIV Counseling and Testing System (HIV CTS) is an information system used to quantify HIV counseling and testing services delivered in publicly-funded sites and to determine the characteristics of persons receiving those services. These data are used by prevention programs to plan and target services for high-risk individuals.

Two types of HIV counseling and testing data are available. In 41 areas, a standardized abstract of each counseling and testing interaction is prepared at the testing site and forwarded to a central health department office where a centralized data base is maintained. The following data are collected on the abstract form: Name of the area receiving funds, counseling and testing site type and site identification number, date of visit, demographic variables (gender, age, race/ethnicity, state, county, zip code), health insurance provider, reason for visit, risk factors, previous HIV test and results (client elicited), whether testing was anonymous or confidential, test result, date and results of post-test counseling. No personal identifiers are collected on the abstract form.



In 24 areas, all publicly-funded sites periodically compile a standardized aggregate summary of the services provided in their setting. Aggregate summary data are also forwarded to a central health department office where the data base is maintained. These aggregate reports include name of the area receiving funds, calendar quarter in which services were delivered, number tested and number positive for each risk group, number tested, number positive, and number post-test counseled by type of test site, and number tested and number positive by race/ethnicity, gender, and age group.

**Target Population:** Clients who receive confidential or anonymous HIV counseling and testing services in 9,960 publicly-funded sites. Some private sites (i.e., that do not receive public funds to provide counseling and testing services) are also included at the discretion of the state, territory, or local jurisdiction. In participating sites, all clients receiving these services are included by means of a client-specific abstract or inclusion in a site's aggregate summary data.

**Funded Sites:** All state health departments, the U.S. territories, and 6 local health departments (New York City, Philadelphia, Chicago, Houston, San Francisco, Los Angeles).

**Strengths:** Between these two approaches, there is a standardized system for collecting and analyzing data about HIV counseling and testing services funded with HIV prevention cooperative agreement funds. All areas receiving federal HIV prevention funds use one of the two systems and have at least summary data by type of site, about the number of persons receiving counseling and testing services and the proportion of persons seropositive by testing site. Areas using the client-specific abstract have very detailed data, by site, on the number and characteristics of persons tested and their test results. In these areas site data can be obtained for local jurisdictions that have publicly-funded HIV counseling and testing sites.

**Limitations:** This system is distinct from the blinded, clinic-based HIV seroprevalence survey conducted in selected areas. While the former survey generates an estimate of HIV seroprevalence that is unbiased by client self-selection, the CTS system only includes clients who seek out counseling and testing services or agree to be tested after consultation with a counselor at a clinic site. However, for those clinic sites in which clients can obtain services other than counseling and testing for HIV, and in which all or nearly all clients actually receive HIV counseling and testing, data from

the HIV CTS for those sites (using the standardized client abstract) approximates the reliability of the blinded surveys, and these data are available to local areas. The HIV CTS includes patients who are tested multiple times. It is not possible to distinguish individuals who have been tested multiple times, except by the "previous HIV test" variable in the standardized client abstract.

#### 4.2.2 HIV/AIDS Data Available to Many States

**4.2.2.1 HIV Infection Surveillance.** Currently, 25 states require reporting of diagnosed HIV infections. This provides information on persons with earlier stages of HIV infection (compared with AIDS reporting) but is more dependent on patterns of HIV testing.

**Stated Objectives and Overview:** The objectives of HIV infection reporting are to: 1) provide a minimum estimate of the number of HIV-infected persons and the extent of HIV-related morbidity and mortality; 2) provide a means to identify and characterize persons with more recent HIV infection than persons with AIDS; 3) identify changing patterns in the modes of HIV transmission; 4) guide the development, implementation, and evaluation of public health intervention and prevention programs; and 5) provide linkages for referring HIV-infected persons to prevention, medical, and social support services. Standardized case report forms and software are used for local data tabulations and to report HIV cases (without names) monthly to CDC.

**Target Populations:** Persons found to be HIV-infected in states with named HIV infection reporting.

**Strengths:** HIV infection reporting provides a minimum estimate of the number of known HIV-infected persons and can be used to anticipate trends in HIV infections among particular populations (e.g., children, adolescents, women), which may not be apparent from AIDS surveillance. It also provides a basis for establishing and evaluating linkages to the provision of prevention and early intervention services. In states that have evaluated HIV infection reporting, completeness of reporting of HIV cases is estimated to be 80%-90% of those persons who tested positive for HIV. Health departments have a well-established record of protecting the confidentiality of HIV case reports from unauthorized or inappropriate disclosure or use.

**Limitations:** Data on HIV infection reporting is limited to those states that require HIV infection reporting by name. The 25 states that require named HIV reporting now report about 23% of total U.S. AIDS cases. Of the 10 states with the highest rates of AIDS, only New Jersey has named HIV reporting. HIV reporting laws and regulations are not uniform, and surveillance practices vary widely. As a result, information provided with HIV reports varies. For example, approximately one-third of HIV reports do not include information on the mode of HIV transmission. HIV reporting is incomplete because many persons who are infected have not been tested. Funding for active surveillance for HIV infection cases began only recently, in late 1991. In general, community advocates have opposed HIV infection reporting because of concerns regarding its impact on the use of HIV testing and because follow-up linkages to services are insufficient in many areas.

**4.2.2.2 HIV-Related Hospitalizations.** Many states maintain computerized records of hospitalizations. The data can be used to describe HIV-related hospitalizations.

**Stated Objectives and Overview:** The primary objectives are to enumerate and characterize severe morbidity attributable to HIV infection using data from computerized hospital discharge records. Data are abstracted from medical records. Each discharge record typically lists from one to seven diagnoses, which are encoded according to the International Classification of Diseases, Ninth Revision, Clinical Modification (ICD-9-CM). Diagnostic codes specific for HIV infection (042, 043, 044) were introduced in 1986. Discharges with HIV diagnostic codes provide a minimum estimate of HIV-related hospitalizations because HIV infection or AIDS may not be specified on the hospital discharge records of some HIV-infected patients.

**Target Population:** These data sources generally reflect discharges from nonfederal, short-stay, general, and specialty hospitals.

**Strengths:** These data are useful for examining trends in annual HIV-related hospitalizations. Such analyses can be stratified by patient demographic characteristics and by hospital characteristics. Data on length-of-stay are generally available, and cost data may be available. Detection of HIV-related hospitalizations depends only on routine recording of discharge diagnoses on hospital discharge summaries. It does not

require special efforts by physicians or other health-care workers to report cases. With certain exceptions (e.g., Veterans Administration Hospitals), the data represent generally both large and small HIV-care providers in states.

**Limitations:** The data do not represent morbidity in persons not hospitalized. However, most severe morbidity is likely to be treated in hospitals. The unit of analysis is the hospital discharge record, not the patient, and an individual patient could have multiple hospital discharges. The presence of a diagnosis of HIV infection as the first-listed diagnosis on the hospital record does not necessarily mean that HIV infection was the principal reason for hospitalization. Data are not collected on the patient's mode of exposure to HIV infection. Longitudinal follow-up of individual patients or hospitals is not possible.

#### 4.2.3 HIV/AIDS Data Available to Selected Areas

A number of blinded HIV seroprevalence surveys are conducted in selected areas.

##### 4.2.3.1 HIV Sentinel Hospitals Survey

**Stated Objectives and Overview:** The HIV Sentinel Hospital Surveillance System monitors and detects HIV seroprevalence in populations at 39 acute-care hospitals in metropolitan areas throughout the United States. The study design includes a sampling scheme that is weighted by age and sex to reflect the general population served by the hospital. Unlinked (blinded) HIV antibody tests are performed on blood taken routinely upon admission. Demographic data and documented medical conditions about the sampled patients are obtained.

**Target Population:** Patients of all ages at large acute-care hospitals in selected U.S. metropolitan areas.

**Strengths:** This survey obtains HIV seroprevalence rates that are unbiased by patient self-selection. HIV seroprevalence rates are analyzed by documented medical conditions. Persons of all ages are sampled.

**Limitations:** Associated risk behaviors are not obtained from patient interviews or medical chart review.

##### 4.2.3.2 Clinic-based HIV Serologic Surveys

**Stated Objectives and Overview:** HIV seroprevalence is measured in sentinel health clinics (sexually trans-

mitted disease clinics, drug treatment centers, tuberculosis clinics, women's health clinics, homeless health centers, juvenile detention facilities, and adolescent clinics) that serve persons with varying levels of risk for acquiring HIV infection. Participating clinics conduct unlinked surveys that follow standardized protocols to monitor seroprevalence for clinic clients over time. Residual blood collected for routine diagnostic purposes is tested for HIV antibodies after all identifying information has been removed, and HIV risk information corresponding to the specimen is recorded. CDC and state and local health departments also bank residual sera for possible future study.

**Target Population:** Persons with varying levels of HIV risk seeking treatment at selected clinics in 20 major metropolitan areas of the United States.

**Strengths:** These surveys obtain HIV seroprevalence estimates that are unbiased by client self-selection. These data have been useful locally in documenting both the presence and extent of HIV infection in a variety of population groups, motivating communities to respond.

**Limitations:** It is often difficult to interpret trends in HIV seroprevalence rates from these annual surveys due to possible changes within clinic populations. Prevalence trends may not accurately reflect incidence trends, particularly when the prevalence is relatively high compared to incidence.

**Note:** CDC has proposed implementing a rapid assessment protocol that would enable communities to quickly assess HIV prevalence in targeted groups. Health departments could use this protocol to implement one-time or intermittent serosurveys in sites of local priority.

In addition, CDC in collaboration with selected areas, is assessing the feasibility of combining the use of a serologic marker of the duration of infection with standard seroprevalence methods. This may enable the use of cross-sectional surveys of HIV prevalence to also estimate HIV incidence in the surveyed populations. New technologies for measuring CD4<sup>+</sup> T-lymphocyte counts will allow for such assessments, combined with the development of statistical methods to interpret these data.

#### 4.2.3.3 The National Death Index (NDI) Project

**Stated Objectives and Overview:** The primary objectives of the NDI project are to: 1) evaluate the completeness of death ascertainment by AIDS surveillance;

2) obtain information on the causes of death of persons with AIDS; and 3) estimate the extent to which persons change residence from time of diagnosis to death.

The National Death Index (NDI) is a computerized index of death records submitted to the National Center for Health Statistics (NCHS) by the state vital statistics offices. The NDI was established to assist health investigators in determining whether persons in their studies have died, and, if so, in which state. NDI provides death certificate numbers, and investigators may then purchase copies of death certificates from the appropriate state offices. Data are currently available for deaths occurring up to 1990; the lag time is related to collection, preparation, and computerization of death certificate data by all state vital registrars.

In this project, state health departments submit to the NDI names of persons reported with AIDS (or in some states with HIV infection) to identify unreported deaths. *This project does not seek to identify new AIDS cases or evaluate the completeness of AIDS case reporting.* Rather, it will evaluate the completeness of death reporting among persons who have already been reported as having AIDS (or HIV). Because CDC does not collect names of persons reported with AIDS (or HIV), the linkage with the NDI must be done by local/state health departments that have primary responsibility for AIDS surveillance. The project is, thus, an extension of routine efforts of health departments to ascertain the vital status of persons with AIDS. Because of concerns with security and confidentiality, a staff member of each participating health department hand-carries the AIDS surveillance data file to the NDI computer at Research Triangle Park, North Carolina once a year and ensures that no AIDS surveillance data remain at the NDI facility upon departure.

In addition to ascertaining vital status, other information from death certificates (e.g., causes of death, place of death, marital status) is obtained for all persons who have been identified through the AIDS case report system and who have died. Data are entered into a supplemental section of the HIV/AIDS Reporting System.

**Target Population:** All persons reported with AIDS in funded areas (or with HIV infection in states that conduct named HIV reporting).

**Funded Sites:** Arizona, California, Colorado, Florida, Maine, Maryland, Massachusetts, Missouri, New Jersey, New Mexico, Rhode Island, and Washington, Los Angeles County, San Francisco, New York City.



**Strengths:** These data are useful in estimating the completeness of reporting of HIV-related mortality, measuring migration patterns, and changing patterns of terminal care with death certificate data from a large sample of persons with AIDS.

**Limitations:** Data collection is dependent on the delay in reporting of death certificate information of 1-2 years. Project also reflects accuracy of cause-of-death information on death certificates.

#### 4.2.3.4 Pediatric Spectrum of Disease Project

**Stated Objectives and Overview:** Much remains to be learned about the pediatric HIV epidemic in the United States. AIDS surveillance is critical in providing information on children meeting the AIDS surveillance case definition. In states with HIV reporting, brief information is now available on all children identified as infected. Further information comes from prospective clinical studies such as those conducted by the AIDS Clinical Trials Groups. These projects, however, are capable of following only a small portion of the infected children. Thus, there is a need for a more thorough and broad-based description of HIV-related illness in children.

To address this need, CDC instituted a multi-center, active surveillance project in 1988. The goals of this project are to: 1) describe the demographic characteristics of HIV-exposed children; 2) describe the spectrum of morbidity and causes of mortality among these children; 3) assess when and why children are initially evaluated for HIV infection; and 4) describe what constitutes standard medical care.

Data are collected on a standard data collection form, entered into a CDC-designed software system at each site that allows local analyses, and forwarded to CDC without personal identifiers. Detailed instructions and intensive support help to ensure uniformity in data abstraction across sites. The information collected on each child initially and every 6 months afterward includes: demographic characteristics; mode of HIV exposure; diseases in the 1987 AIDS surveillance case definition and the Pediatric HIV Classification System; laboratory data; treatment and prophylaxis for HIV and specific related conditions; and causes of death when applicable. Documentation of immunizations is obtained from inpatient and outpatient records. Information on individual hospitalizations is collected on the follow-up forms for each 6-month period.

**Target Population:** All children under 13 years of age, who were HIV-infected or born to infected mothers and who had been seen at one of the participating institutions are eligible for inclusion. Children who are eligible for inclusion are identified by contact with key practitioners at each hospital. Project personnel visit the participating institutions on a regular basis to identify children eligible for the project.

**Funded sites:** Los Angeles County Department of Health; the New York City Department of Health; the Texas Department of Health (Houston, Dallas, and San Antonio); the Massachusetts Department of Health; Children's National Medical Center, Washington DC; and Stanford University, Palo Alto CA.

**Strengths:** The project: 1) provides a high quality and large quantity of data available on a sample of children exposed to HIV; 2) allows for active surveillance in hospitals, where 23% of 1991 pediatric AIDS cases were reported; and 3) enables the tracking of trends over time, including changes in clinical practice in response to published guidelines (e.g., PCP prophylaxis guidelines).

**Limitations:** Data are obtained by abstraction of the medical records; therefore, information not documented in the medical record is not obtained. The rural population of HIV-exposed children is not well represented.

**Note:** Due to the increase in tuberculosis among the population at risk for HIV, this project has recently added questions to the data collection form to determine the prevalence of TB skin testing and the incidence of TB diagnosis among children enrolled. Additional funding has been allocated to the New York City site to conduct further surveillance for TB disease.

#### 4.2.3.5 The Adult and Adolescent Spectrum of Disease (ASD) Project

**Stated Objectives and Overview:** The primary objectives of the ASD Project are to enumerate and characterize persons with HIV infection at various stages of immunologic function who receive medical care at selected inpatient and outpatient facilities. Information is collected on AIDS-defining conditions, other illnesses and symptoms, treatments, and laboratory measures of immune status from available medical records using a standardized data collection form. Data are collected for the 12-month period preceding

ascertainment, and data collection continues with reabstractions every 6 months.

Data are entered into microcomputers by local project personnel, using standardized computer software containing validation checks. Data can be analyzed locally. Evaluation studies of the completeness of data for both clinical conditions and laboratory parameters have been conducted locally.

**Target Population:** In these funded areas, more than 90 facilities (clinics, hospitals, neighborhood health centers, private medical practices, and emergency rooms) were selected as project sites. Persons 13 years of age or older with a diagnosis of HIV infection who received health care at the participating facility are eligible for inclusion in the project. All HIV-infected women and persons of minority racial or ethnic groups who are identified for the project are included. Because of the large number of white men at some sites, 25% to 50% of white men were systematically sampled at some of the participating facilities in Michigan (Detroit), Texas (Dallas, San Antonio), and Washington (Seattle).

**Funded Sites:** Los Angeles County, Colorado, Georgia, Louisiana, Michigan, New York (New York City), Washington State, Texas (Dallas, Houston, San Antonio), and Puerto Rico.

**Strengths:** This project describes the spectrum of HIV disease as documented in medical records and is useful in assessing use of recommended prophylaxis and treatments and in evaluating the AIDS surveillance definition and the HIV classification system. Data collection has been ongoing since January, 1990—more than 18,000 persons have been included.

**Limitations:** Project is limited to persons who have received medical care for HIV infection and limited to medical record review at selected facilities. Thus, the project is dependent on the thoroughness of diagnostic testing and recording, and underrepresents diagnoses made and recorded elsewhere.

**Note:** The ASD data collection form has been revised, primarily to expand data collected on gynecologic conditions and tuberculosis. Gynecologic information will include use of Pap smears and cervical cytology results. Tuberculosis-related information will include date of the earliest positive tuberculin skin test or the most recent negative test, results of delayed type hypersensitivity skin tests, history of active pulmonary TB, and use of smears and sputum cultures. Drug susceptibility information will also be collected.

#### 4.2.3.6 Clinic-based Surveys of Risk Behavior

**Stated Objectives and Overview:** Surveys of HIV risk behaviors have been conducted at corresponding clinic sites in tandem with the seroprevalence surveys. While these surveys are no longer ongoing, their data may be useful to community planners in gauging the extent of HIV risk behaviors in selected groups. Surveys of risk behaviors (linked to results of voluntary HIV counseling and testing) were conducted in selected clinics through December 1992. The purpose of the risk behavior surveys was to obtain detailed information about behaviors that may be associated with HIV infection. This information was collected during a structured interview using a standardized risk assessment questionnaire. Risk behavior surveys were conducted in conjunction with HIV counseling and testing programs in sexually transmitted disease clinics, women's health clinics, tuberculosis clinics, drug treatment centers, and among homeless populations. With the exception of homeless populations, only clinics and centers that offered HIV counseling and testing and appropriate follow-up services were eligible to conduct risk behavior surveys. Since sufficient numbers of seropositive clients needed to be enrolled to compare risk behaviors with uninfected persons, clinics selected for risk behavior surveys had high seroprevalence rates demonstrated by unlinked surveys.

**Target Populations:** Persons with HIV-associated risk behaviors seeking services at selected clinics in 44 selected major metropolitan areas of the United States.

**Strengths:** These surveys were conducted in multiple cities using standardized questionnaires and data management systems. In clinics conducting concurrent unlinked and risk behavior surveys, risk behavior survey participants composed a subset of clients whose sera were included in the unlinked clinic survey. Comparison of seroprevalence rates in the risk behavior and unlinked surveys is one measure of the local HIV testing acceptance rate and of the ability of a counseling and testing program to reach HIV-infected individuals.

**Limitations:** The results of these risk behavior surveys may be influenced by self-selection bias, i.e., differences among clients in their willingness to participate. To obtain risk behavior information from a large number of infected clients, only selected clinics with relatively high prevalence rates for HIV were included in the surveys. Because of the cost associated with sup-

porting trained personnel to enroll and conduct interviews of participants, risk behavior surveys were more expensive to conduct than unlinked clinic surveys.

**Note:** The project has been discontinued or superseded by new projects to assess HIV incidence among clients of sexually transmitted disease clinics and drug treatment centers. In conjunction with participating state and local health departments, HIV incidence and associated risk behaviors will be estimated and/or directly measured in persons attending drug treatment centers and sexually transmitted disease clinics. These projects will use a dynamic cohort approach with either passive or active follow-up. In sexually transmitted disease clinics, incidence will be measured retrospectively among persons with multiple clinic visits and HIV tests and prospectively in persons at repeated clinic visits. In drug treatment centers, similar methods will be used along with more active measures to encourage clients to return for follow-up evaluations. These studies, which supersede the clinic surveys of risk behaviors, will complement data from the ongoing unlinked clinic surveys without duplicating large cohort studies. Protocols are being developed jointly with participating project areas.

#### 4.2.3.7 Supplement to HIV/AIDS Surveillance (SHAS) Project

**Stated Objectives and Overview:** The primary objective of the SHAS project is to obtain increased descriptive information on persons  $\geq 18$  years of age reported with HIV infection and AIDS. Information is collected using a standardized questionnaire administered by trained interviewers. The questionnaire consists of modules covering the following topics:

- demographic-socioeconomic information;
- drug use history, both injected and non-injected;
- sexual behavior history;
- use of health care services;
- reproductive history and children's health (women only); and
- information on disabilities (to be added).

Interview data are entered into microcomputers by local project personnel, using standardized software containing validation checks. This software allows for local analyses.

**Target Population:** Persons reported with AIDS; in some states, persons reported with HIV infection.

**Funded Sites:** Arizona, Colorado, Connecticut, Delaware, Florida, Georgia, Michigan, New Jersey [began in 1993], New Mexico, South Carolina, Washington, and Los Angeles County.

**Strengths:** Behavioral data are collected that can be used to evaluate prevention and intervention programs. Access to care and disability measures will be evaluated to determine in more detail health-care needs of all HIV-infected persons. More detailed data than are routinely available are provided on race/ethnicity and on the socioeconomic factors that affect health.

**Limitations:** Because data are based on self-reported information, accuracy of some information may be variable. Limits on detail reflect time constraints in administering questionnaire.

### 4.2.4 National Systems That Do Not Provide Local Data

In addition to the projects outlined in this document, CDC conducts a variety of more detailed research projects in collaboration with local health departments and/or local hospital-based or university-based researchers. These projects include behavioral research projects, studies of the natural history of HIV infection in men and women, studies of selected opportunistic infections, studies to prepare for future vaccine trials, and evaluations of methods for providing early intervention services for HIV-infected persons. In addition, in communities funded by the Ryan White Care Act, the Health Resources and Services Administration funds data collection on diagnostic and therapeutic services provided to clients and descriptive information regarding clients. These data should be available from local agencies that administer Ryan White Funds.

#### 4.2.4.1 Behavior Monitoring Systems Supported by CDC

**National Survey of Family Growth (NSFG):** This periodic national survey of about 10,000 women ages 15-44 years is conducted by the National Center for Health Statistics. This is a survey about family formation and reproductive patterns and practices, but it includes questions about number of partners, sex with injecting drug users or bisexual men, condom use, HIV testing (no results), self-assessed risk, and changes in

behaviors related to HIV. The last NSFG was conducted in 1988, with a follow-up interview in 1990. The next study will be in 1994, with several follow-up interviews at 18-month intervals.

*National Health Interview Survey (NHIS):* The NHIS is a continuous national survey of about 50,000 households conducted by NCHS. The data collection is done by the Bureau of the Census. The NHIS consists of 1) a core interview covering a range of health-related topics for which a household respondent answers for all family members; and 2) special supplements that usually change from year to year. Most of the supplemental topics are asked of one randomly selected person household. A supplement on HIV attitude and knowledge has been asked since August of 1987.

#### 4.2.4.2 Behavior-Related Surveys Not Supported by CDC

*National Household Survey of Drug Abuse:* This national survey, sponsored by the National Institute on Drug Abuse and the Substance Abuse and Mental Health Services Administration, has been conducted periodically for the last 2 decades and annually since 1990. The current design involves about 30,000 individuals,

with oversampling in a number of large metropolitan areas. The questionnaire includes most, if not all, of the essential HIV-related drug use questions. Beginning in 1992, the design was modified to permit quarterly estimates of national drug use.

*National Health and Social Life Survey:* This study, conducted by the National Opinion Research Center and supported by a group of private foundations, was based on much of the initial planning for the proposed National Institute of Child Health and Human Development Survey of Health and AIDS-Related Practices. The study, a national area-probability survey of adults ages 18-59 years, was conducted in 1992 by using personal interviews averaging about 90 minutes in length with a completion rate in excess of 75% (3,100 respondents). Data are currently being analyzed.

*National AIDS Behaviors Survey:* This study, funded by a grant from the National Institute of Mental Health, was conducted by the Center for AIDS Prevention Studies at the University of California, San Francisco. About 10,600 persons ages 18-75 years were interviewed by telephone between June 1990 and February 1991. The sample was composed of two groups: 1) a national sample of 2,673 people; and 2) a sample of 8,263 people in "high-risk" cities.

# Chapter 5

## Assessing and Setting Priorities for Community Needs

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The Community Planning Process	Community Planning Tasks	Additional Resources
1. Ensuring Community Participation 2. Valuing and Managing the Community Planning Process 3. Conflict of Interest and Dispute Resolution	4. Developing an Epidemiologic Profile 5. Assessing and Setting Priorities for Community Needs 6. Setting Prevention Program Priorities 7. Selecting Among HIV Prevention Interventions: Theoretical Basis, Effectiveness, and Cost-Effectiveness 8. Evaluating the Community Planning Process	9. Resources for HIV Prevention Community Planning



# Chapter 5

## Assessing and Setting Priorities for Community Needs

### 5.1 OVERVIEW

The intent of this chapter is to assist planning groups to implement a needs assessment, as outlined in CDC's *Supplemental Guidance on HIV Prevention Community Planning* (Section B). The purpose of such a needs assessment is to:

- assess existing community resources for HIV prevention to determine the community's capability to respond to the epidemic;
- identify unmet HIV prevention needs within defined populations; and
- prioritize HIV prevention needs by defined high-risk populations.

This chapter reviews basic needs assessment principles for HIV prevention planning and the steps involved in conducting a thorough and useful needs

assessment. At the end of the chapter there is a section entitled "Notes From the Field: Assessing and Setting Priorities for Community Needs." This section presents findings from a series of interviews with state AIDS directors and other staff regarding their experience with needs assessment activities.

A needs assessment may be the first task of the project area's HIV prevention community planning group. It is an important process that uses epidemiologic and other qualitative and quantitative data as the basis for making informed decisions about the adequacy of services available to a given population. The development of an epidemiologic profile, as a component of the needs assessment, is an important way of identifying and defining the high-risk populations in a specific project area. Chapter 4 discusses the relevant issues associated with this element of needs assessment.

Intense community involvement in the needs assessment process means that all parties will feel that resources are allocated and policy decisions made on the basis of a systematic and objective process that documents the needs of all populations. In this way, the planning group builds a solid foundation for overall planning, implementation, and evaluation of HIV prevention activities.

In addition to community participation, the success of a needs assessment process is determined by: 1) the selection of a basic approach that is appropriate for the project area under study; 2) an understanding of the desired results before engaging in the process; 3) the collection of data from a variety of sources, both quantitative and qualitative; 4) an accurate analysis of the information gathered; and 5) the identification of important needs.

#### Definitions

**Needs assessment**—The process of obtaining and analyzing findings through multiple methods of information and data collection to determine, through community participation, the type and extent of unmet needs in a particular population or community.

**Primary data**—Data that are newly collected specifically for a task.

**Secondary data**—Existing data that are gathered and used in a project.

## 5.2 PRINCIPLES OF CONDUCTING A NEEDS ASSESSMENT

As discussed by CDC in the *Supplemental Guidance* (Section D), certain principles should guide planning groups in planning and conducting needs assessment activities as part of the community planning process.

These principles should be reviewed and agreed upon by all participants in the process. Before beginning each task of the needs assessment, groups may find it useful to address each principle and assure themselves that the task adheres to the applicable principle(s). These principles are shown in Table 5-1.

The process of a needs assessment cannot be circumscribed within a rigid, textbook-type approach. Above all, the process must remain flexible, with all

**Table 5-1: Needs Assessment Principles of HIV Prevention Planning**

- The starting point for defining future HIV prevention needs begins with an accurate epidemiologic profile of the present and future extent, distribution, and impact of HIV/AIDS in defined, targeted populations within the project area.
- In defining at-risk populations, special attention should be paid to distinguishing their behavioral, demographic, and racial/ethnic characteristics.
- Identification, interpretation, and prioritization of HIV prevention needs reflect culturally relevant and linguistically appropriate information obtained from communities to be served, particularly persons at risk for HIV infection and persons living with HIV.
- Assessment of HIV prevention needs is based on a variety of sources (both qualitative and quantitative).
- Prevention needs data are collected using different assessment strategies (e.g., surveillance; survey; formative, process, and outcome evaluation of programs and services; outreach and focus groups; public meetings).
- Needs assessment incorporates information from both providers and consumers of services.
- Specialized techniques, such as over-sampling, may be needed to collect valid information from certain at-risk populations.

participants willing to be creative with the activities at hand. Each project area is unique, with differing levels of resources, available data, and technical expertise. In addition, participants are working within different and often complex political and social contexts that can affect the needs assessment process. These factors contribute to the concept that the use of mul-

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*"Qualitative data helped our state health department come away with a far better understanding of the challenges of HIV prevention. It helps you address the audience, market the message, and most importantly helps you understand why people are engaged in certain behaviors."*

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multiple methods, in which a project area picks the most feasible methods from a variety of possible choices, is the best approach and actually produces the most useful results.

It is important to remember that a needs assessment examines issues at a particular point in time, providing a "snapshot" of the HIV epidemic and resulting needs in a given community. Therefore, it should not be viewed as a one-time activity, but rather as an important aspect of an ongoing cycle of program planning, development, implementation, monitoring, and evaluation. Each needs assessment process should build upon the last and contribute to improving the next one. With shifts in the communities affected by the epidemic and new trends being identified, AIDS presents project areas with a unique challenge to reassess continually their prevention efforts.

## 5.3 COMPONENTS OF EFFECTIVE NEEDS ASSESSMENT

Regardless of the approach or methods used, the needs assessment process is generally comprised of the following basic steps:

- formulating questions
- selecting a basic approach
- collecting data
- analyzing data
- identifying needs and service gaps



### 5.3.1 Formulating Questions

Before beginning any needs assessment process, the planning group must decide what questions need to be answered. A common pitfall is to immediately argue about the pros and cons of various methodologies (i.e., should we hold a public hearing or conduct a survey?) without taking the time to consider what the participants specifically want to find out about HIV prevention needs in their community.

The planning group also needs to recognize that formulating these questions is a continuous process. As shown in Figure 5-1, the needs assessment process is iterative. Available data are reviewed along with the decisions to be made. Questions that cannot be answered from the available data are prioritized and additional data collected and analyzed, which can lead to more questions. This cycle then begins again. The participants should not be afraid to revisit these tasks to ensure that the process stays on track and precious time and resources are not wasted.

The planning group can begin with general questions, such as:

- What does the epidemic look like and where is it going?
- Who are the communities and target populations in need?
- What issues or problems are these populations facing?
- What resources are currently serving these populations and how?
- How effective or adequate are existing services?

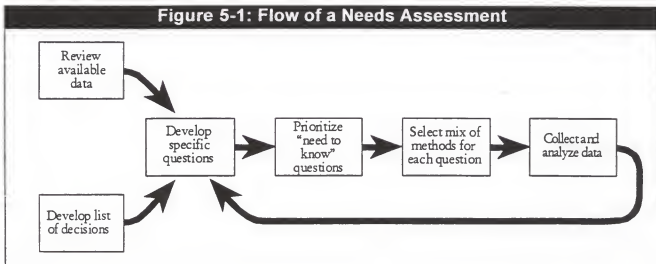
More detailed questions will arise as available data are reviewed. For example, in answering questions about resources, the planning group may want to define more specifically the existing prevention activities and determine how they are distributed throughout the area (e.g., how many organizations are distributing condoms, to whom, where?). This type of activity is called a resource inventory and is described later. In examining the communities in need, it will not be enough to describe the communities by categories of race/ethnicity alone. The planning group may realize that characteristics, such as age, gender, sexual orientation, and socioeconomic status, within these categories are also key to understanding HIV prevention needs.

More specific questions can be generated through group techniques, such as brainstorming, where everyone is encouraged to offer suggestions and extensive lists are created. These questions should then be prioritized into "need to know" versus "would like to know" categories, thus establishing the basis for the needs assessment.

### 5.3.2 Selecting a Basic Approach

Another major task in completing a needs assessment is deciding upon the basic approach that will be used to answer the formulated questions. In planning for the process, the participants need to determine the scope and depth of the assessment that is feasible for the group. For this task, it is helpful to keep in mind the intended use and users of the needs assessment. The results of the needs assessment will be used by the planning group to identify the most important prevention needs in the community for which programs and interventions should be developed.

**Figure 5-1: Flow of a Needs Assessment**



*Planning and Evaluating HIV/AIDS Prevention Programs in State and Local Health Departments: A Companion to Program Announcement #300* (CDC, 1993) is a useful resource that groups common approaches to needs assessment into three categories. These approaches differ in the extent to which they either involve formal calculation of quantitative data or use more informal methods of qualitative data and social interaction:

**Group I: High Degree of Formal Calculation/Low Degree of Social Interaction**

- relies more on quantitative data collection and calculated formulas, such as structured surveys, demographic data, and health status indicators

**Group II: Medium Degree of Formal Calculation/Medium Degree of Social Interaction**

- involves a balance of formal calculation and social interaction

**Group III: High Degree of Social Interaction/Low to Medium Degree of Formal Calculation**

- examines needs through less statistically-quantified methods, such as focus groups, key informant surveys, and community forums

The specific design of a planning group's needs assessment will depend upon many factors, including the extent of existing data, available resources, available time, experience, and skills of the participants, and the complexity of the epidemic in the project area. In addition to these factors, three other issues merit consideration.

The first is community values. Community planning means that different sets of values will be included in the process. It may not be easy to reach consensus on the most appropriate approach. One group of participants may not want to address a problem, whereas others will perceive a need to explore the issue. HIV prevention program providers may view a service differently than the consumers of the service. Politics and the history of HIV prevention in the community may be powerful determinants in the selection of methodologies. Some may even fear how the results of the assessment will be used in their community. It is better to address explicitly values and expectations during the process, rather than try to dismiss or avoid them.

Second, careful thought should be given to the skills needed to guide and support the process. The ability to collect and analyze data and communicate results in a clear, objective manner is essential. Differ-

ent techniques require different types of skills; those who are qualified to convene a public hearing may not be the same as those who conduct a survey. The planning group will need to decide who will actually conduct the needs assessment. Perhaps outside expertise will be sought (i.e., academicians/researchers, other health departments, HIV-related organizations, consultants, national organizations, or area foundations). Planning group members may bring their own skills or know others in the community who can be of assistance. The AIDS program staff of the health department may draw upon additional resources in other areas of the health department (e.g., TB, surveillance, health education, drug abuse). The planning group may want to form a standing committee to direct this activity.

Finally, there is the need to incorporate multiple methods of information-gathering, as expressed in the *Supplemental Guidance*. The use of both quantitative and qualitative methods for assessing need allows for increased accuracy and greater objectivity. The drawbacks of increased cost and complexity of the analysis are outweighed by the higher quality of the product. The selection of an approach appropriate to the project area means considering the advantages and disadvantages of each approach as well as the ultimate purpose (e.g., what questions are being answered through this approach?) and the resources available.

### 5.3.3 Collecting Data

After developing the list of questions to be answered and selecting a basic approach, the planning group should put its needs assessment activities in writing. This "plan to plan" should include tasks, accountable individuals, and deadlines. A written plan for the needs assessment process means that the agreed upon approach and critical milestones are understood at the beginning by all participants. The planning group should consider the resources available to carry out the needs assessment and how best to allocate these resources. Participants should then establish a timetable for the tasks that realistically accounts for possible constraints. This activity may actually serve to better focus the activities as community members review and comment upon the document. Flexibility will still remain an integral part of the process; the "plan to plan" will most likely be revised later to reflect new ideas or unanticipated events.

Before deciding upon activities for collecting new data, participants should review any relevant existing data. For example, community-based organizations

may have recently completed a survey of their clients or an earlier planning process for a particular population may have yielded valuable information. These existing data are termed “secondary data” as opposed to newly collected, or “primary data.”

Secondary data sets that can assist the completion of the needs assessment may include the sources shown in Table 5-2 as well as others unique to the project area.

Before embarking on any primary data collection activity, the planning participants must ask how the data elements will be used and how the information will fit into the entire process. In other words, the project area should distinguish the information that they would “like to know” from what they “must know” in order to develop an effective HIV prevention plan. This kind of questioning will enable the project area to focus limited planning resources and create a product that meets their needs.

Again, it should be emphasized that using multiple methods, both quantitative and qualitative, often yield more balanced and comprehensive information for decision-making than does one method only (U.S. Conference of Mayors, 1990). Qualitative methods provide descriptive information about situations,

events, and/or behaviors of individuals. This information might be obtained from a variety of sources, such as direct participant feedback or program documents. Quantitative methods yield statistical profiles (e.g., numbers, percentage change). Examples include amount of services delivered; incidence of HIV infection; and changes in knowledge, attitudes, and behavior. Qualitative and quantitative data can complement each other. The numbers derived from survey results can be enhanced by the comments of a focus group.

**5.3.3.1 Data Collection Methods:** In deciding which specific data collection methods to use, the planning group should first consider several key issues (McKillip, 1987; U.S. Conference of Mayors, 1993):

**Cost:** Existing data are less expensive to use than conducting new, large surveys.

**Time:** Surveys take the most time, followed by focus groups and then the use of existing data.

**Skills:** Designing surveys and organizing a community forum require different kinds of expertise.

**Table 5-2: Sources of Secondary Data**

- AIDS surveillance and HIV seroprevalence information (see Chapter 4 of this document for more detail on profiling the epidemic);
- STD and TB surveillance data and other health status indicators;
- Health department clinic data, including family planning and substance abuse treatment;
- Behavioral risk factor and quantitative knowledge, attitudes, beliefs and behavior (KABB) studies;
- Program administrative records, which may detail services provided and populations reached;
- Information from any previously conducted needs assessments, whether completed for the entire community or for a particular organization or population within the community;
- Census data and local updates, which provide information on socioeconomic characteristics of residents, by area;
- Information about human services in the area, including publicly and privately funded agencies and organizations, which will be used for the resource inventory;
- Social and political information and historical issues that provide the context for planning activities (these issues may be discussed in local newspapers and agency memoranda);
- Socioeconomic information, e.g., data on homelessness, mental health, teen pregnancy, immigration, school drop-out rate; and
- Substance use information, which could include drug mortality rates, and emergency room drug-related admissions, in target populations.

**Problem versus Solution Orientation:** Some techniques help to identify problems of the target population, others suggest solutions, and some can be designed to do both. For example, survey questions or focus group discussions could be designed to look at current issues facing a community or could address successful interventions;

**Flexibility:** All the data elements for a comprehensive resource inventory may not be available, but most methods can be adapted to the circumstances of the project area.

**Detail:** Surveys produce data that allow project areas to make generalizations, while focus groups and hearings yield more specific anecdotal information.

**Credibility:** Different data sources are perceived as more credible than others, for example, some participants may trust census data more or less than other sociodemographic indicators.

**Community Support:** Some methods allow for more community participation than others; activities such as focus groups and community forums not only provide relevant information but also can increase awareness and enlist support.

In the area of data collection techniques, the CDC guidance refers to "oversampling" as a means to collect information about at-risk populations.

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*"We developed a needs assessment using several data sets; we intend to use focus groups, and client surveys as well to help us develop a profile of HIV in our state."*

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Oversampling is a process in which one selects more people from a segment of a larger population than the percentage they represent in that larger population. Oversampling is done in order to obtain a sufficiently large number of people from this segment to be able to describe them validly.

Several important data collection methods for determining community capacity and assessing community opinion are described in the boxes located at the end of the chapter, including: Resource Inventories, Focus Groups, Surveys, Key Informant Interviews, and Community Forums/Public Hear-

ings. Planning groups may also choose to employ additional methods that are not described within this chapter. For example, individuals involved in completing a needs assessment often neglect to participate in meetings already regularly attended by the community. In other words, the process can be a two-way street in which members of the public attend forums convened by the planning group and the planning group members actively participate in events organized by others.

### 5.3.4 Analyzing Data

After new and existing needs assessment and utilization of services data have been collected, planning groups will be faced with the challenge of analyzing and interpreting the information. It is advisable to involve all available experts (e.g., planners, epidemiologists, statisticians) both within and outside the planning group in the process to review the needs assessment findings and to help interpret the results. The goal is to identify the trends affecting HIV prevention in the community. The group should determine what is occurring over time in different population groups, in terms of the epidemiology of the epidemic, services utilized, and other factors.

Of course, methods of analysis depend on the questions asked and the data collection methods used. Quantitative findings from needs and services data can be presented in simple tabular form that will easily reveal the discrepancies that exist between certain priority population needs and the services that currently exist in a particular area to meet those needs. Qualitative data, such as information from focus groups and key informant interviews, do not lend themselves to tabular presentations. Different approaches to analyze and present such findings may be required.

The data and information collected through resource inventories can be compared with other needs data to help the project area identify which service providers are responding to the needs and demands for services of certain populations. These comparisons of services and needs data can help reveal the unmet needs, gaps in, and barriers to HIV service delivery. In analyzing the results of focus groups, it is important to look for trends and patterns in participants' beliefs and opinions.

### 5.3.5 Identifying Needs and Service Gaps

Careful analysis and interpretation of needs assessment findings from a variety of data sources should

allow the planning group to delineate both met and unmet needs of priority populations and identify gaps in HIV prevention services. This component of needs assessment should consider gaps and needs in terms of: defined populations (e.g., behavioral, demographic, racial/ethnic, linguistic, and cultural characteristics); types of HIV prevention services (e.g., educational and other materials, peer interventions, street outreach, school-based programs); geographic distribution (e.g., accessibility throughout the project area); and other issues unique to the project area.

The planning group members should become essential players in this process. Their perspectives and knowledge about the community should be used to collect and interpret data and identify major needs and gaps. If they are presented with the data in a comprehensive and comprehensible way, these community representatives should be able to offer important insights into which needs are unmet and possible reasons why. The planning group may want to come to agreement on the ideal set of HIV prevention services for their community and compare this ideal to the reality presented by the data.

Analyzing use of services to determine gaps and unmet service needs involves: 1) identifying percentages of client subgroups that make up the total client population; 2) computing rates of services used by each subgroup of clients; and 3) comparing the number of clients served with the number of people expected to use the services. Comparing expectations for use of prevention services to actual use should reveal discrepancies, gaps, unmet needs, or problems in services utilization.

The final step in this gaps analysis involves determining barriers and factors that either inhibit or facilitate use of prevention program services by the client or priority population. Planning group members can be especially instructive on this component. Issues of service awareness, availability, accessibility, and acceptability need to be considered. Physical, financial, and time constraints; cultural perceptions of needs; and competing services offered by other agencies are all factors that can influence use of services by special populations and client groups.

The relationship between use of prevention services and the need for such services is complex and difficult to assess. Increased use of services may also result in increased demand. Waiting lists and full capacity of services may indicate need for additional services in certain communities and among certain population groups. However, limited use of ser-

vices may also indicate need, especially when the service is related to HIV prevention and its benefits are not widely understood. Data on non-users of services may reveal why existing services are underutilized and how such services can be improved to meet needs of certain populations. Such information may also indicate the need to find alternative approaches or create new systems for delivery of services that may result in greater responsiveness to the needs of these groups.

## 5.4 PRESENTING THE DATA

Select members of the planning group or the entire group should review preliminary findings and documents generated by the needs assessment. If a committee is formed, it should reflect a diverse membership to incorporate various perspectives in decisions on data presentation. They may determine the number and sequence of needs assessment reports and approve initial report outlines. Their comments and critique can help to strengthen final drafts and build ownership for the document within the group.

Regardless of how they are published, most reports include a brief summary with the goals of the project clearly stated; methods (what was done, how and when it was done, who did it); and findings (responses to questions, observations, problems discovered, resources available, potential obstacles, etc.). Most importantly, the analysis must be conveyed clearly, concisely, and without jargon in a neat, uncluttered, and easy-to-read style.

Brief documents that visually summarize findings can be powerful tools. Visual aids also make data more easily understandable to a diverse audience. These tools include maps, bar graphs, icons, line graphs, and pie charts. Yet, it is important to always keep the audience in mind. In one instance, a coffin placed as a visual next to statistics on AIDS deaths greatly distracted and offended audience members, several of whom were living with HIV infection. Qualitative data, such as salient quotes from focus groups and interviews, can encourage interest in and understanding of the quantitative data.

Once the report is completed, the next step is the dissemination of findings. Careful thought to the dissemination of the final needs assessment report and communication of the results is critical to ensuring acceptance of the entire planning process. While the planning group will have flexibil-

ity in how it presents the data, it must consider the intended audience(s) for the data, including their differing levels of expertise. Epidemiologists may have a perspective on the data that differs from providers in a community agency. Each of these perspectives should be valued for the added insight they bring to the process.

The group must decide how widely it wants to disseminate its needs assessment findings. The impact of the needs assessment can be broadened beyond the HIV prevention community planning process by distributing the report to local policymakers and the media. Some groups may wish to prepare a public document that is widely distributed to public and private agencies and at local conferences, professional meetings, and/or community organizations as an indication of unmet needs in the community. A good dissemination strategy developed collaboratively by the planning group may improve communication, coordination, and collaboration among community groups in the planning process and resulting priority activities.

In some cases, the timing in dissemination may become an important issue. For example, the Austin/Travis County HIV Commission realized that it had to publish its needs assessment before the city's budget deliberations in order to have an effective impact on the budget process (U.S. Conference of Mayors, 1992A).

The planning group may choose to distribute several reports on the needs assessment process, or publish one report that summarizes findings from all activities. Or, it may want to wait to include all the information within a final, detailed plan. The presentation of a series of reports provides several advantages: a large amount of information may be more easily absorbed, a sense of progress in the process may be communicated, and any revisions in methodology based on the information may be incorporated. Time and other resource constraints may have to be considered in this approach.

Any data presentation can be judged against three characteristics:

- **Accuracy.** Planning groups should verify calculations and report any inconsistencies. While it is not possible to include every detail, accuracy means being complete and addressing facts that may conflict with personal positions.
- **Documentation.** Those who have developed the reports should provide sufficient documentation so

that facts can be checked. The shortcomings and underlying assumptions of the data or analysis should be reported.

- **Fairness.** Since the planning group's approach will most likely include multiple methods, diverse views and explanations will be gathered. Therefore, any final analysis should present facts that support the various viewpoints. The work of others and secondary data sources used in the analysis should be cited.

It is important to note that the audience for the data may include those who favor quantitative methods over qualitative methods and vice versa. The hard work that goes into collecting and analyzing data should not be wasted because a poor presentation allows the audience to discredit the results. Presenters should be able to clearly describe methodologies and address any questions regarding the process. If project areas are honest about shortcomings of the data and describe these issues from the beginning, the findings may be more widely accepted. CDC's Planned Approach to Community Health (PATCH) process provides some useful "Do's and Don'ts" on presenting data in its "In a Nutshell" fact sheets (CDC, 1992). These materials also provide additional information on developing handouts and overheads. These suggestions are summarized in Table 5-4.

## 5.5 ESTABLISHING PRIORITIES FOR NEEDS

Once the planning group has identified risk, disease trends, needs, and gaps in service, they must begin one of the most challenging aspects of HIV prevention community planning: establishing priorities for needs. The participants must use all the information gained from the needs assessment to answer the difficult question: "Which of the HIV prevention needs and gaps identified in our community are the most important for us to address?" As described by CDC in the *Supplemental Guidance* (Section D), certain principles should guide project areas in addressing this question, as follows:

- Setting priorities is shared between organizations administering and awarding HIV prevention funds and the communities for whom prevention services are intended.



**Table 5-4: Do's and Don'ts of Presentations**

**Do:**

- Cover the highlights. Cover what is unusual, either in a number or by trend; what differs from national or state statistics; what is the finding on a topic of particular concern to the community.
- Stimulate interaction. After a brief presentation of highlights, solicit questions about any items of special interest to the participants.
- Organize. Make sure information requested by participants can be quickly retrieved.
- Highlight the findings that relate to items identified in other data sources. For example, if the focus groups discussed high-risk behaviors, the group might present behavioral science data on these behaviors. By placing data results within a familiar context, greater understanding and interest are promoted.
- Use visual supports as much as possible. Clear, simple charts and graphs get the point across better than lists of numbers. Keep graphics simple; use one general topic and not more than five sub-topics on each visual support.
- Make the data interpretation easy to understand and interesting, so that participants will be intrigued and excited about their data.
- Illustrate the value/uses of data in decision-making and in designing effective HIV prevention programs.
- Summarize. Spend the last two minutes of a data presentation quickly reviewing the major findings so participants do not get lost among all the facts. Give participants summary handouts.

**Don't:**

- Give a staged presentation that lasts over a half-hour.
- Try to present everything.
- Crowd visual supports with too much information, several different types of information, or unnecessary words.
- Use statistical or scientific jargon.

CDC, 1992

- Setting priorities for HIV prevention needs reflects culturally relevant and linguistically appropriate information obtained from the communities to be served, particularly persons at risk for HIV infection and persons with HIV disease.

In addition to the above principles, the planning group should consider several key issues when determining priorities for needs: populations, resources, and the distribution of these resources. The needs assessment analysis should have indicated the populations of concern to the community (e.g., what do the epidemiologic trends reveal about emerging populations at risk for HIV infection?). The resource inventory will allow participants to understand how the community is currently addressing the epidemic in terms of programs, targeted groups, etc. The distribution of these resources among populations as well as among geographic regions of the project area will be an important factor in determining which needs are more critical than others. For example, the group may conclude that Latina adolescents in a particular region of the project area are a high priority for HIV prevention services because the epidemiologic and other data demonstrate their increasing risk for HIV infection and relatively few resources are currently targeted to this population in this region.

Planning groups should understand that setting priorities, as with the resolution of other differences, will occur in a group process with the community's involvement. As discussed in Chapter 2, the planning group must establish ground rules and processes for decision-making early, before beginning the major task of a needs assessment. Group agreement on effective work strategies and operating procedures will become even more critical at this juncture in the plan's development. The greater the individual member's understanding of how the group has agreed to manage the process, the more smoothly each component of needs assessment, including setting priorities, can be implemented. If the planning group is experiencing major difficulties, Chapter 3 provides some useful strategies for understanding and resolving group disputes.

CDC has provided for considerable flexibility regarding setting priorities and other decision-making processes. Each planning group will need to determine the approach that works best for them. The literature and public health resources offer instructions and worksheets for various methods of priority setting. Three techniques—the ranking model, the nominal group technique, and the Delphi—may prove useful to the planning group. CDC's PATCH process pro-

vides step-by-step instructions for the nominal group technique. APEX/PH materials describe in more detail the ranking of public health problems. Several methods, including the three described here, have also been discussed in the technical assistance documents provided to Ryan White CARE Act Title I grantees by the Bureau of Health Resources Development. Contacts for further information on these techniques appear in at the end of this chapter. In addition, Chapter 6 of this handbook discusses in more detail an approach to making decisions and setting priorities for HIV prevention needs and interventions.

The planning group chair may suggest one or more of these models to the group and, if agreement is achieved regarding the model's feasibility, the technique could be used. A brief overview of the three methods follows.

### 5.5.1 The Ranking Model

In a ranking model, participants establish a relevant set of criteria and assign a priority ranking to problems based upon how they measure against the criteria. For example, each problem may be assigned a priority of I, II, or III with Priority I problems being those on which corrective action could and should begin immediately (CDC, 1991). A score of one to ten is assigned to each problem on each of the criteria. A problem with a score of ten on each criterion would indicate that it has the greatest priority. Participants assign a priority rank based on where the total of its criteria scores fall (i.e., problem receives Priority I if it scores between 21 and 30 based on three criteria scored one to ten).

Criteria usually include the following:

- Magnitude of a problem: How much of a burden is placed on the community, in terms of financial losses, years of potential life lost, potential worsening of the problem, etc.?
- Seriousness of the consequences of the problem: What benefits would accrue from correcting the problem? Would other problems be reduced in magnitude if the problem were corrected?
- Feasibility of correcting a problem: Can the problem be solved with existing technology, knowledge, and resources?

Other criteria might include whether the problem is perceived as serious by community leaders and members and whether incentives exist to respond to the problem.

### 5.5.2 The Nominal Group Technique

The nominal group technique is a small group discussion technique that results in a priority ranking of answers to various need analysis questions. Specific questions are posed (e.g., "What do you consider to be the priority populations for HIV prevention, from those identified in the needs assessment?") and discussed in a structured and formal manner. Participants react individually to the questions, write down responses, and share them with the group. The group then discusses all responses and rank orders ideas in importance of need. The goal is to generate as many ideas as possible in order to have a comprehensive discussion about a specific topic or area of interest. Groups may vary in size, but all require a well-trained facilitator.

As with any technique, several disadvantages exist (Siegel et al., 1987). The nominal group technique lacks precision; votes or rankings are made without careful or thorough sorting out of all the ideas generated into appropriate categories. Another disadvantage is that, while most participants enjoy the process and may feel satisfied with the results, some participants may feel manipulated because they are not used to participating in such a highly structured process. Careful planning, preparation of group members, and follow-up feedback to the group can minimize these problems.

### 5.5.3 The Delphi Technique

The Delphi technique allows for systematic collection and analysis of informed judgments on a particular topic or issue. While used primarily to predict or forecast needs, Delphi panels may also set priorities among needs. Delphi panels are comprised entirely of experts who use a series of self-administered questionnaires. A facilitator solicits information from the experts, provides feedback on their responses, and gives them an opportunity to revise their responses. The process is completed when the experts no longer alter their responses.

A description of this technique was provided to Ryan White CARE Act grantees, as follows. A first questionnaire would provide an open-ended format for participants to "indicate those items that you feel are the top priority service needs of persons with AIDS and HIV disease in the [funded areas]." A second questionnaire to the same group would provide collated categories from the first questionnaire and ask for a ranking and comment on each of the items.



A third questionnaire would provide an initial vote total for every item plus a summary of participants' comments and ask participants for a final ranking of the priority areas. This final ranking is collated and used as the list of priority prevention needs.

The process is labor-intensive and time-consuming, but it can generate very informative data. Differences of opinion can be resolved without forcing face-to-face confrontation and the controlled manner of the feedback reduces negative influences of individual vested interests. Since responses are anonymous, group pressure to conform is significantly decreased. There are several disadvantages. The technique lacks certainty in guidelines on its use and design. Many "modified" Delphi techniques exist because practitio-

ners do not agree on the answers to fundamental questions (e.g., is the respondent group completely anonymous, how many iterations are needed, what form should the feedback take). Also, extreme positions are often dropped to obtain agreement and consequently, diverse and creative ideas may be lost.

In identifying priority needs, the project areas must be guided by the epidemiologic data and take into consideration each project area's own distinct mix of political and economic conditions, funding and administrative constraints, and overall health and social problems. With the completion of a needs assessment and with the establishment of priorities for needs, the planning group is ready to consider intervention strategies.

## Resource Inventories

A resource or community inventory is among the most critical means of primary data collection. CDC defines the assessment of existing community resources for HIV prevention, including fiscal, personnel, and program resources from public, private, and volunteer sources, as an essential component of HIV prevention community planning. The inventory usually results from a survey of service providers and yields a listing or summary of information about certain services provided by organizations in a defined geographic area. The basic question addressed by the inventory is "Who is doing what for whom?" Some of the many purposes for completing a resource inventory are to:

- identify the range of organizations and agencies in the community that are serving various target populations;
- estimate service utilization (the number of clients being served) and service capacity (the number of clients who could be served);
- identify community leaders and gatekeepers who have access to target populations and who would need to be involved in any intervention;
- identify gaps in community services, including the various populations both served and underserved, and the geographic distribution of HIV services;
- understand the capabilities, philosophy, functions, and goals of organizations;
- obtain information about potential linkages among organizations involved in similar or complementary activities; and
- obtain information about the potential for coordinating community activities.

Although a resource inventory is a method used to survey existing program and service resources rather than to direct need in a community, planning groups may want to consider using the survey as a needs assessment tool. Service providers completing the inventory could be asked about what they perceive as the HIV prevention needs of their clients. The answers, in combination with other methods for assessing need, can assist planning groups in identifying whether adequate response exists to the needs of target populations.

As with any data collection method, the planning group should consider how the inventory will be used before beginning to collect the information. The group should gather any previously developed inventories and the surveys used to create them. These materials may serve to assist the planning group in deciding the format for the final inventory and other design issues.

A resource inventory includes the seven basic steps listed below. For a more detailed description of these steps, planning groups should refer to *Planning and Evaluating HIV/AIDS Prevention Programs in State and Local Health Departments: A Companion to Program Announcement #300* (CDC, 1993), which contains a chapter devoted to conducting resource inventories.

- Define geographic area and level of analysis for inventory.
- Determine categories of service provider agencies.
- Select service provider agencies for inventory.
- Identify service provider representatives.
- Construct the resource inventory.
- Contact service providers and conduct inventory.
- Compile and analyze inventory data.

## Focus Groups

Focus groups are an important data collection tool in the needs assessment process. They are a form of guided group discussion with a homogenous group of five to ten individuals, a moderator, and, if possible, a recorder. A permissive and non-threatening environment is created in which open-ended questions are used to analyze how participants feel about a topic. Group dynamics are encouraged so that participants build upon each other's opinions or discussion points. The moderator keeps the discussion focused and solicits participation from all members, but does not unduly influence its direction.

Planning groups can use focus groups to have community members generate or screen new ideas, provide preliminary guidance, identify key issues, or provide insights into the needs and opinions of a target population. This technique allows project areas to discover how people think about various ideas, what they feel, the level of intensity attached to their attitudes, and the meanings they attach to things. Focus groups can also complement quantitative data collection methods.

In some situations, focus groups are not helpful. If the issues are so sensitive that individuals cannot discuss them in a group, then this information collection technique should not be used. When the planning group needs data on actual behavior, not what people think they should do, other methods should be implemented. Also, for this method to be useful, the groups must be free of peer pressure; participants should not feel inhibited in the discussion. Focus groups are not meant to provide definitive answers or finalize difficult choices for the planning group.

Several issues that will assist the process should be considered. The planning group should decide how it wants to present the purpose of the focus group to its participants. A group discussion guideline, which addresses any procedural issues, outlines the purpose of the group and lists three to five basic questions, should be developed before the groups are conducted. This guideline is used by the moderator to ensure groups are conducted in a consistent manner.

The number and type of groups depends upon the characteristics of the project area. For HIV prevention planning, groups organized around target populations are useful. Usually, focus group sessions last about 90 minutes. Consistency in approach and greater ease in analyzing results can be achieved by conducting the groups over a relatively short time, i.e., four groups in two to four days.

Participants can be recruited through any number of convenient methods. They are not expected to constitute a representative or random sampling of any population. Clients of HIV prevention agencies, including individuals living with HIV infection, bring an important perspective to the group. They can be recruited through agencies or directly from agency waiting rooms or by word-of-mouth. Community leaders can also be sources for participants. A small monetary incentive, gifts, vouchers for other services, and/or snacks can further encourage participation. With some populations, childcare and transportation considerations will have to be addressed. While sessions can be held in office conference rooms, settings within the community with which participants are familiar and comfortable may ensure attendance and open discussion.

While the moderator could be a grantee staff person or member of the planning group, it is highly recommended that a "non-aligned" facilitator who is perceived as objective should moderate the session. The moderator should have some knowledge of HIV prevention issues and affected populations. If possible, moderators should be of a similar background to the participants. Regardless of the person or persons chosen to act as moderators, they should all receive joint training or orientation to ensure that the different focus groups follow consistent procedures. Ideally, a trained outside expert should lead the groups, or train volunteers to do so.

A recorder, or individual present to take notes, can be very useful because it frees the moderator to concentrate on the group. While sessions can be tape recorded for later transcription, the group's permission should be received first. It should be noted that tape recorders can often inhibit discussion or raise concerns about how the recording will be used.

## Surveys

Surveys can take a number of forms and provide a means for finding out information about a community or target population, service providers, or other groups. Data can be collected on knowledge, attitudes, and behaviors; demographic characteristics; and service provider characteristics. Project areas may find surveys useful when information is needed from large numbers of people, questions can be clearly defined, quantitative results are desired, and anonymity is important.

The term "survey" is often used with a variety of meanings. A survey can denote an extensive study of the needs and resources of a large community or a brief and superficial study of the situation of a particular organization. Surveys can have different focuses or aims. They can range from assessments of available community resources to assessments of client satisfaction with services.

There are three different types of survey methods generally used in needs assessment (McKillip, 1987):

*Face-to-face interviews* allow for in-depth discussion of needs and may be most appropriate in addressing hard-to-reach populations. These interviews often require extensive staff time, for both the planning and the interview itself. Costs can often be high.

*Telephone interviews* also permit in-depth discussion but can be more cost-effective and less labor-intensive than in-person interviews. Interviewers can be monitored for accuracy if telephoning occurs from one location.

*Mailed surveys or questionnaires* provide a flexible method for gathering large samples of responses. They typically contain a combination of forced response (i.e., yes-no answers, scales, checklists) and open-ended questions. They can be expensive and time-consuming, especially if extensive follow-up for non-respondents is required. Response rates for mailed surveys tend to be low.

In order to execute a survey, a number of activities are involved (Orkand Corp., 1979). These are outlined below. Five sets of written materials should result: an initial rough plan or proposal, analysis plan, instrument, sample design, and fieldwork plan (e.g., training manual). Activities include:

- Develop initial rough plan or proposal with objectives, potential approaches, timeline, resource requirements, and action steps and discuss with planning group.
- Make decision regarding use of outside expertise and have these individuals involved as early in the process as possible.
- Define objectives of survey in detail to address data items and analysis at a relatively general level.
- Select survey type (i.e., phone, mail, or face-to-face);
- Identify data items to be collected by developing a complete list of specific items.
- Design analysis plan to specify exactly how each data item in the list developed above will be used.
- Design survey instrument to avoid interviewing errors and the ensuing analysis problems (instruments should be simple, reproducible, and valid).
- Design sample to be surveyed, with outside assistance, to reduce the magnitude of error and allow results to be generalized to the larger population.
- Design fieldwork procedures with step-by-step instructions for everyone involved, i.e., how will survey be conducted and by whom.
- Recruit and train survey staff to ensure consistency and comparable responses.
- Conduct pretest and deliver survey to sample.
- Prepare data for analysis by checking for consistency and completeness.

## Key Informant Interviews

Key informant interviews are a type of survey that involves community members who represent important constituencies with a knowledge of or experience with HIV prevention problems and solutions. They are leaders (community, religious, etc.), public officials, administrators, and service providers who are aware of the needs and services perceived as important by a community. Such interviews can focus needs assessment efforts on specific issues and may help to increase communication and cooperation among agencies and services. Typically, results will include some fairly concrete statements of need.

Key informant surveys are quick and relatively inexpensive to conduct, although it is a challenge to produce a good questionnaire and to analyze resulting data. The project area can retain the flexibility to use either a structured (mailed questionnaire) or an unstructured (face-to-face interview) format.

A disadvantage is the possibility of professional biases on the part of the key informants. They may have an organizational perspective on community needs and a bias toward the activities in which each is involved. Key informant reports will often overestimate problems facing the target population and underestimate the community's ability to solve these problems. To minimize possible bias, more than one person who represents a certain constituency should be interviewed.

Key informant interviews should be conducted with individuals who are selected based upon the longevity of their involvement in the community and/or the nature of their involvement with the community. These individuals should be chosen to cover the full range of community opinion. In some cases, political and geographic balance among informants may be an important consideration.

The interviews, which should last one to two hours, are conducted from a list of questions about the existing services in the community and/or about certain demographic characteristics of the population. Interviews should include questions on both general and specific needs of the population as well as issues of accessibility and acceptability of solutions. The interview sessions can be open-ended and conversational while still following the outline of questions previously developed. Project areas can request not only factual information, but the interviewee's opinions about specific issues. A mailed or telephone notice of the interview before it takes place will encourage participation and maximize information. The notice should include a basic outline of the purpose of the interview and the questions to be asked.

During the interview, the interviewer should be sensitive to new information and take advantage of unexpected "leads." When an answer raises an important point that was not part of the developed questions, the interviewer should pursue it. Although the interviewer may feel the need to keep the interview on track, it can be useful to shift to the informant's topic. On the other hand, if the informant is on a tangent that seems unimportant, the interviewer can use the questions to steer the conversation back to the relevant concerns.

For truly successful interviews, the interviewer should possess or develop (U.S. Conference of Mayors, 1992B) the following skills. He or she should:

- be able to ask the right questions and to interpret the answers;
- be a good listener and not trapped by his or her own ideologies or preconceptions;
- be adaptive and flexible, so that newly encountered situations can be seen as opportunities, not threats;
- have a firm grasp of HIV prevention issues so that relevant information to be sought is more manageable; and
- be unbiased by preconceived notions so that contradictory information can be met with sensitivity and responsiveness.

## Community Forums and Public Hearings

Community forums or public hearings are data-gathering techniques from the political arena. They consist of a series of public meetings for the purpose of involving community residents to define and discuss needs. Community forums are generally less formal and are open to the public, while public hearings consist of testimony from selected witnesses and issuance of a summary report. These kinds of activities are an inexpensive, relatively easy-to-arrange approach to needs assessment. They can also raise the credibility of the needs assessment process by enhancing openness and inclusion.

Public meetings are used more for informing decision-makers than for making actual decisions. Forums and hearings can result in community awareness and understanding of the entire planning process and resulting activities. Project areas may find that this method is an excellent opportunity to build community investment and ownership in HIV prevention efforts.

As a note of caution, project areas should recognize that public forums require broad representation since the needs identified depend on the characteristics and backgrounds of those who participate. Community members who choose to participate in forums are often activists or advocates who want an opportunity to speak out on a certain issue. They may represent those whose needs are being assessed but may not be completely representative of the project area's clients or the community.

Importantly, the ground rules for the event should be decided early and explained at the meeting: the way in which speakers are identified, time allotted for each speaker, format for questions and answers, etc. This pre-planning will prevent misunderstandings among community members and a "free-for-all" atmosphere that can discourage participation. These rules may be put in writing and made available at the meeting so late-comers are aware of the format. The project area may want to consider whether written testimony will be required or encouraged. The use of skilled facilitators and small break-out groups can help to ensure that the process keeps focused on needs identification and allows participation by all attendees.

A number of elements that are essential to a successful public meeting are listed here:

- The planning group members must agree on the purpose of the event and be willing to articulate this purpose. Some project areas have found it useful to make it clear that the forum is expressly for hearing about priority needs of the community, and not funding requests from individual organizations.
- The project area must widely publicize the event. Planning group members can distribute flyers at their affiliated organizations and invite community leaders and representatives of target populations. Announcements should be placed in several community media outlets, not just one newspaper.
- The locations should be chosen with the idea of encouraging community participation, and the facility should be able to accommodate the audience comfortably.
- Support items will be necessary to ensure a smoothly-run meeting. Extra microphones and lecture stands will mean less distractions if equipment fails. Audio taping of the event may be desired. Organizers should provide a sign-in sheet for attendees for accurate record-keeping and any necessary follow-up (e.g., thank-you's, invitations to other events).

## 5.6 REFERENCES AND RESOURCES

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Zucconi, S. L., et al. *Assessing Community Health Needs: Implications for Health Care Reform*. Pittsburgh PA: University of Pittsburgh Health Policy Institute, 1993.



## RESOURCES

Assessment Protocol for Excellence in Public Health (APEX/PH) and  
A Guide for Establishing Public Health Priorities  
Public Health Practice Program Office  
Mailstop E-20  
1600 Clifton Road  
Atlanta GA 30333  
Contact: William Dyal

Planned Approach to Community Health (PATCH) Program  
Division of Chronic Disease Control and Community Intervention  
National Center for Chronic Disease Prevention and Health Promotion  
Centers for Disease Control and Prevention  
Mailstop K-46  
1600 Clifton Road  
Atlanta GA 30333  
Contact: Charles Nelson

Technical Assistance to Ryan White CARE Act Grantees (various materials)  
Planning and Technical Assistance Branch  
Division of HIV Services - Bureau of Health Resources Development  
Health Resources and Services Administration  
Parklawn Building  
5600 Fishers Lane  
Rockville MD 20857

# Notes From the Field:

## Assessing and Setting Priorities for Community Needs

### OVERVIEW

The state AIDS directors who were interviewed seemed to have differing opinions and varying levels of experience with the needs assessment process. Some states indicated that needs assessment was a weak area for them on a statewide basis, whereas others felt confident about their experience and competencies. The challenge in pulling together an effective needs assessment for some was related to the size of their states, the diversity of their populations, and the availability of adequate resources. For other respondents, the lack of useful needs assessment instruments and tools and appropriate methodologies seemed to be a barrier. Experience with using various quantitative and qualitative methods for assessing needs varied by state. Some concluded their states needed to place greater emphasis on quantitative methods. Others valued the contribution of qualitative data.

All the respondents concurred on the importance of using needs data to set priorities among needs and to base community planning decisions on solid evidence derived from such data. When reflecting on past planning activities, one state, which had a positive experience with Title II planning, indicated, "One change we'll make during HIV prevention community planning is to do a better job on needs assessment....We're going to try and do a very scientific needs assessment....We'll have more emphasis on quantitative data." This state in the past had used statewide provider and client surveys to assess need but did not feel these methods were useful in helping to distinguish among priorities.

### USING QUANTITATIVE DATA TO PROFILE THE COMMUNITY

Use multiple sources of quantitative data. All the states interviewed used HIV epidemiologic data as part of their planning efforts and seemed knowledgeable in using such data to help construct community profiles. One state, however, was concerned that much of the epidemiology and behavioral science research data collected by the state health department "does not tell us what is going on in our smaller cities, rural areas, small towns, and suburbs." This respondent thought that rapid, small cell assessment methods may be more useful in obtaining information for such areas.

Most respondents mentioned other kinds of quantitative data they have either used in the past or plan to use to help assess community needs during the forthcoming community planning process. Two years ago, one state developed a needs assessment that it thinks will be useful to its new community planning committee. This assessment was developed using multiple data sets. The data sets that the state found most useful in completing the needs assessment included the following:

- HIV seroprevalence data
- AIDS surveillance data
- National HIV Survey of Childbearing Women
- STD surveillance data
- Teen pregnancy data
- Youth Behavior Risk Factor Surveillance System data

In addition to such data sets, this state intends to use other tools to determine need, such as focus groups and client surveys. It is envisioned that the collection of data to assess needs in the future will be much more participatory in terms of the community. This state has also had prior experience in using the Healthy Decisions Effort model, through the department's Office of External Affairs. This model entails a process of getting community input into identifying the health values of a community and results in a ranking of community values. The Healthy Decisions Effort will be adapted for the purposes of needs assessment and used during the community planning process for HIV prevention.

### Prevention Planning Profile

Massachusetts has previously undertaken an HIV services needs assessment in relation to HRSA funding requirements. This was an 18-month needs assessment process that yielded five-year projections for the state. It was an inclusive process that involved many different task forces and committees with community participation. This earlier needs assessment process has produced a successful model that will be adapted by the HIV prevention community planning group.

### USING QUALITATIVE METHODS TO ASSESS NEEDS

**U**nderstand the value of using qualitative data. Some respondents seemed to have extensive experience in using qualitative methods to identify needs. One state had convened focus groups in twelve different locations throughout the state. The attendees of these focus groups were chosen to represent certain target populations at risk. The questions in these groups focused on how specific interventions should be designed to reach and address the needs of different populations, such as gay men of color, sex partners of injecting drug users, rural populations, and sex workers. Interest was expressed by other respondents in learning more about focus groups and having some staff trained in focus group techniques.

Another state used KABP data obtained through a phone survey to develop baseline data to see where the general population was with respect to HIV and

AIDS. These data were then used to convene several focus groups to ask more targeted questions, especially around attitudes.

The focus groups were also used to ask community leaders "what should we do?" Information from these groups was then used to take next steps in terms of a prevention program. Although this state based its formal needs assessment in 1993 on epidemiologic data that enabled it to come up with target geographic areas and targeted groups, it concluded that qualitative data "are far more helpful than quantitative data because they are more useful to hear people's experiences, their knowledge and attitudes. Qualitative data pick up on fine subtleties."

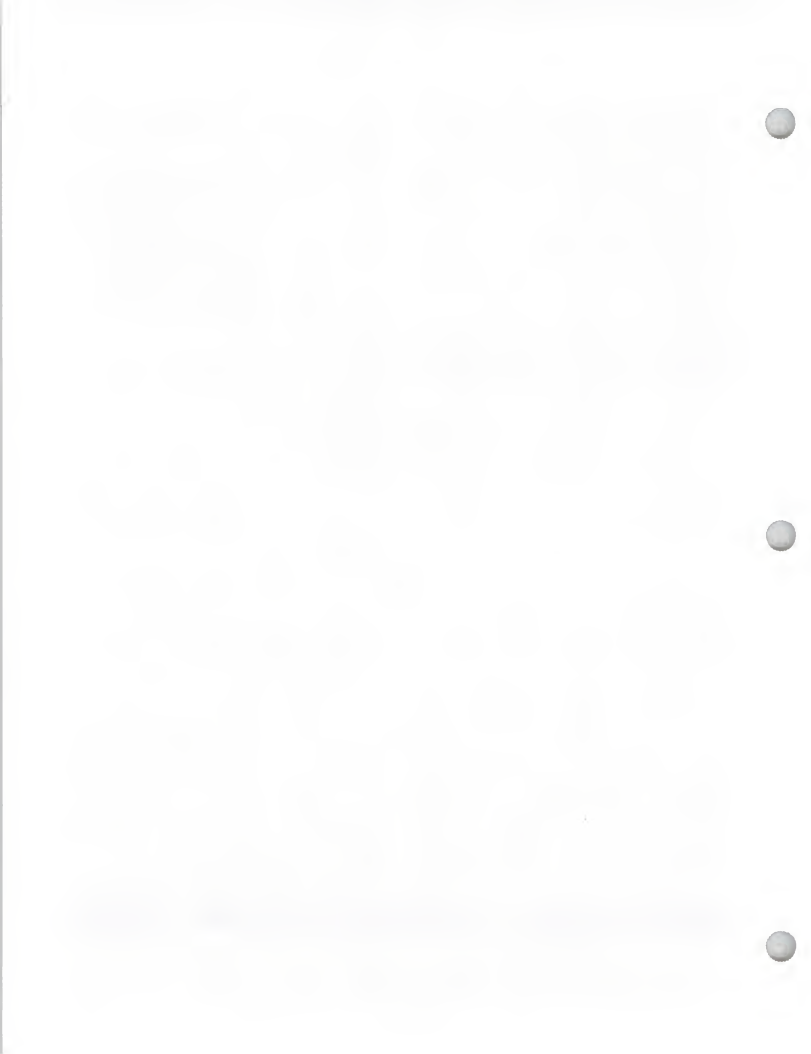
The state AIDS director stated, "Qualitative data helped the state health department come away with a far better understanding of the challenges of HIV prevention. It helps you address the audience, market the message, and most importantly helps you understand why people are engaged in certain behaviors."

### Lessons Learned About Assessing Community Needs:

- Take steps to ensure that certain segments of the population who may have been underrepresented in previous needs assessment are represented in current data collection efforts.
- Use both quantitative and qualitative data to help assess needs.
- Design specialized, targeted training that is customized to the different levels of expertise and knowledge of epidemiology and other types of data that will exist in the various community planning groups.
- Needs assessment should be an inclusive process that involves many different sources.
- It is possible to develop a needs assessment process with lots of community participation in combination with a good use of epidemiology and planning expertise.
- Use focus groups to learn more about special populations, but play an active role in how they are structured. Work closely with the focus group firms/experts hired to conduct this research.
- Work with behavioral scientists and other experts to translate information and data into program plans.

### Prevention Planning Profile

Illinois conducted telephone surveys in 1987, 1988, and 1989 to obtain baseline information about HIV-related knowledge and attitudes of the general population. Some behavioral questions were also asked. These data were useful to the state for planning purposes, but even more useful were follow-up focus groups with special populations that enabled more targeted questioning, especially with respect to attitudes.

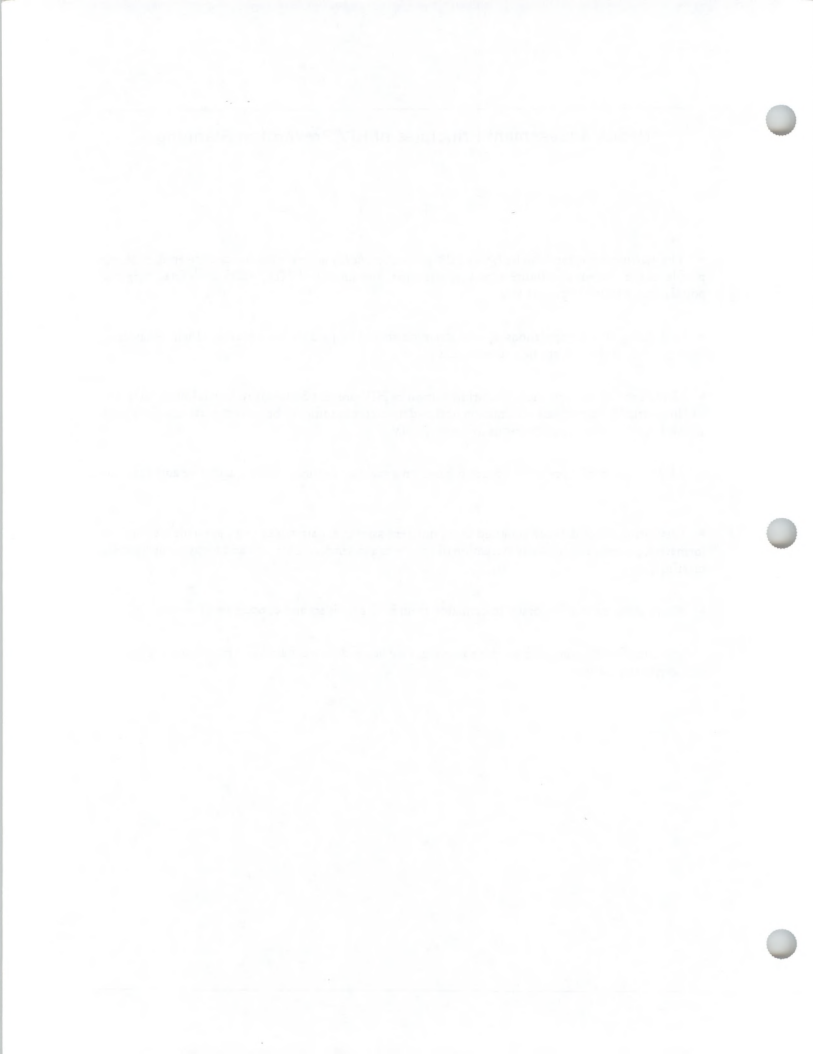


# Handouts



## Needs Assessment Principles of HIV Prevention Planning

- The starting point for defining future HIV prevention needs begins with an accurate epidemiologic profile of the present and future extent, distribution, and impact of HIV/AIDS in defined, targeted populations within the project area.
- In defining at-risk populations, special attention should be paid to distinguishing their behavioral, demographic, and racial/ethnic characteristics.
- Identification, interpretation, and prioritization of HIV prevention needs reflect culturally relevant and linguistically appropriate information obtained from communities to be served, particularly persons at risk for HIV infection and persons living with HIV.
- Assessment of HIV prevention needs is based on a variety of sources (both qualitative and quantitative).
- Prevention needs data are collected using different assessment strategies (e.g., surveillance; survey; formative, process, and outcome evaluation of programs and services; outreach and focus groups; public meetings).
- Needs assessment incorporates information from both providers and consumers of services.
- Specialized techniques, such as over-sampling, may be needed to collect valid information from certain at-risk populations.





## Do's and Don'ts of Presentations

### *Do:*

- Cover the highlights. Cover what is unusual, either in a number or by trend; what differs from national or state statistics; what is the finding on a topic of particular concern to the community.
- Stimulate interaction. After a brief presentation of highlights, solicit questions about any items of special interest to the participants.
- Organize. Make sure information requested by participants can be quickly retrieved.
- Highlight the findings that relate to items identified in other data sources. For example, if the focus groups discussed high-risk behaviors, the group might present behavioral science data on these behaviors. By placing data results within a familiar context, greater understanding and interest are promoted.
- Use visual supports as much as possible. Clear, simple charts and graphs get the point across better than lists of numbers. Keep graphics simple; use one general topic and not more than five sub-topics on each visual support.
- Make the data interpretation easy to understand and interesting, so that participants will be intrigued and excited about their data.
- Illustrate the value/uses of data in decision-making and in designing effective HIV prevention programs.
- Summarize. Spend the last two minutes of a data presentation quickly reviewing the major findings so participants do not get lost among all the facts. Give participants summary handouts.

### *Don't:*

- Give a staged presentation that lasts over a half-hour.
- Try to present everything.
- Crowd visual supports with too much information, several different types of information, or unnecessary words.
- Use statistical or scientific jargon.

## 2. The Role of the State

The state plays a crucial role in the development of a country. It is responsible for providing public goods, such as infrastructure, education, and healthcare. The state also plays a role in regulating the economy and ensuring that the rights of citizens are protected.

In addition, the state is responsible for maintaining law and order and protecting the country from external threats. The state also plays a role in promoting economic growth and development.

The state's role in the economy is particularly important. It is responsible for providing public goods, such as infrastructure, education, and healthcare. The state also plays a role in regulating the economy and ensuring that the rights of citizens are protected.

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# Chapter 6

## Setting Prevention Program Priorities

6.1 Overview	6-1
6.2 Major Types of Formal Decision Analytic Models	6-2
6.3 Core Steps in Decision Analytic Models	6-2
6.4 Community Planning and Core Decision Analytic Steps	6-2
6.5 Additional Considerations in Community Planning Group Decision-Making	6-6
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Handouts	

The Community Planning Process	Community Planning Tasks	Additional Resources
1. Ensuring Community Participation 2. Valuing and Managing the Community Planning Process 3. Conflict of Interest and Dispute Resolution	4. Developing an Epidemiologic Profile 5. Assessing and Setting Priorities for Community Needs 6. Setting Prevention Program Priorities 7. Selecting Among HIV Prevention Interventions: Theoretical Basis, Effectiveness, and Cost-Effectiveness 8. Evaluating the Community Planning Process	9. Resources for HIV Prevention Community Planning



# Chapter 6

## Setting Prevention Program Priorities

### 6.1 OVERVIEW

State, local, and US territory health departments ("grantees"), and community planning groups face many decisions when they prioritize HIV prevention needs and programs. Some suggestions regarding the priority-setting and decision-making processes are provided in the CDC HIV prevention community planning *Supplemental Guidance*, but considerable flexibility is permitted regarding the processes to be used. Although there is flexibility, it is important for grantees and community planning groups to be explicit about their priority-setting processes. If the processes are not made explicit, the resulting confusion over the methods to be used to set priorities can lead to conflict among group members and between the group and the community it represents. Explicitness can remove this source of confusion, and reduce at least some of the potential conflict.

This chapter expands on the *Guidance* and describes in some detail one possible method for making decisions and setting priorities in HIV prevention programs. Although one priority-setting method is outlined here, grantees may use other priority-setting methods if they so desire, provided that they are within the parameters outlined in the *Guidance*.

The sample priority-setting method described here is based on: a) the *Guidance*; b) the practicalities of public health program management; and c) basic decision analytic principles (von Winterfeldt and Edwards, 1986; Sox et al., 1988; Holtgrave et al., 1994). Decision analytic principles are relevant here because HIV prevention priority setting is a decision-making task inherently. Although the priority-setting method described here relies on core decision analytic principles,

doing formal, *quantitative* decision analysis in every community planning group is probably not possible at this time due to inadequate resources to perform all such analyses and difficulties in meeting the data requirements of formal analyses that are custom-tailored to particular communities. Hence the core decision-making principles are used here in a highly simplified fashion.

This chapter proceeds by listing the major core steps prescribed by decision analytic models, and then applying them to HIV prevention priority setting.

### Definitions

**Priority setting**—The process by which a community planning group determines the relative importance of HIV prevention needs and potential interventions.

**Stakeholders**—Those individuals/groups who have a major interest and involvement in a process; in this chapter, stakeholders refers to participants in the community planning process.

**Decision rule**—Refers to a specific method by which a group reviews a series of options and factors in order to come to a decision on a problem at hand.

**Intervention**—An activity whose objective is to change or avert high-risk behavior that may result in HIV infection.

**Prevention program**—A portfolio of interventions designed for reducing HIV transmission among individuals whose behavior places them at high risk of exposure.

Note: This material on priority setting was adapted and extracted from an article by David R. Holtgrave ("Priority Setting and HIV Prevention Community Planning") that is now under review with a journal.

Where necessary, the decision-making steps are augmented with practical suggestions so as to make them useful for real HIV prevention programs. Attention is limited to the problem of prioritizing different HIV prevention interventions; other more complex and quantitative methods exist for prioritizing interventions across public health problems (e.g., interventions for HIV prevention, smoking cessation, water fluoridation, and so on) (Vilnius and Dandoy, 1990; Minnesota Department of Health, 1990; Patrick and Erickson, 1993). However, grantees and community planning groups are free to adapt and use these other more complex priority-setting methods if they so desire.

## 6.2 MAJOR TYPES OF FORMAL DECISION ANALYTIC MODELS

A ny of several formal decision-making models might be applied to HIV prevention programmatic decision-making: a) decision tree analysis (Sox et al., 1988; Raiffa, 1968); b) multi-attributed utility theory (von Winterfeldt and Edwards, 1986; Spear et al., 1988); c) economic evaluation techniques of cost, cost-benefit, cost-effectiveness, and cost-utility analysis (Holtgrave et al., 1994; Holtgrave et al., 1993; Drummond et al., 1987; Detsky and Naglie, 1990; Spear et al., 1988); d) linear programming (Bierman et al., 1986; Gorsky et al., 1993); and e) scenario analysis (Schreuder, 1990). This list of models is not exhaustive but represents major types. Each of these models is used for somewhat different purposes and employs distinct but related methodologies. They all employ a core of common steps used in the analytic procedure. These core steps can be inferred from the references above, and others (Drummond et al., 1987; Udvarhelyi et al., 1992; Ganiats and Wong, 1991). Again, it is recognized that although the core decision-making steps are useful in HIV prevention priority setting, the complete quantitative application of the models may not be possible at this time.

## 6.3 CORE STEPS IN DECISION ANALYTIC MODELS

Most decision-making models include the following core steps:

The identification of ...

1. the key decision-making problem at hand (e.g., which HIV prevention programs to implement);

2. the major stakeholders in the decision-making problem;

3. the perspective to be taken in the decision analysis (e.g., societal, business, individual, or governmental);

4. the time horizon to be considered in the decision-making process (e.g., one, five, ten or more years) and the rate used to discount future costs and events (e.g., zero or five percent);

5. the alternatives (e.g., programs) among which a choice or prioritization is to be made;

6. the attributes (or outcomes) on which the alternatives are to be judged (or valued) (e.g., cost, effectiveness, acceptability to community members);

7. the relative importance weight to be given to the various attributes;

8. sources of uncertainty about the ability of various alternatives to achieve certain outcomes (e.g., probabilities linking alternative programs to outcomes);

9. the decision rule to be used to combine all of the information above (e.g., combining information about a program's score on the various attributes, and the relative importance of the attributes);

10. sources of uncertainty about any parameter described above (and the inclusion of these statements of uncertainty into sensitivity and threshold analyses for determining how robust the decision analytic results are to changes in parameter values).

## 6.4 COMMUNITY PLANNING AND CORE DECISION ANALYTIC STEPS

The application of each of the ten core steps to HIV prevention priority setting is described, in turn, below. Again, community planning groups and grantees may use other priority setting methods provided that they are within the principles of the *Supplemental Guidance*.

### 6.4.1 Decision-Making Problem

The *Guidance* addresses this issue directly. It states that participatory community planning and program priority setting should lead to programs that are effective in preventing HIV infection, and are "...responsive to high priority, community-validated needs within defined populations." Furthermore, the components of an HIV prevention program are listed in

the *Guidance*. The description of program components emphasizes that HIV prevention involves changing or averting high-risk behaviors.

In summary, this *Guidance* language leads directly to the decision-making problem: to prioritize and allocate resources for HIV prevention programs with the goal of changing or averting high-risk behaviors and thereby reducing HIV transmission.

## 6.4.2 Major Stakeholders

It is assumed that the populations of persons required to be represented in the planning groups are stakeholders in the process. CDC states that the community planning process should include "...the views and perspectives of the groups at risk for HIV infection/transmission and for whom the programs are intended, as well as the providers of HIV prevention services." Further, it is stated that the planning groups "...reflect the population characteristics of the current epidemic in state and local jurisdictions in terms of age, race/ethnicity, gender, sexual orientation, geographic distribution, and HIV exposure category." The "current epidemic" is defined in terms of AIDS cases, HIV infection data, or surrogate markers (where available). The community planning groups also must have as members representatives of relevant state and local health and education agencies, as well as other HIV prevention service providers (both governmental and non-governmental). It is clear that such planning group members are stakeholders in HIV prevention programmatic decision-making.

Expertise in the following areas should also be represented on the planning groups: a) epidemiology; b) behavioral and social science; and c) evaluation and program planning. Although this expertise is needed in the community planning process, it is less clear that such experts are stakeholders in HIV prevention programmatic decision-making, if identified merely on the basis of their disciplinary training. At least, they are not stakeholders to the same degree (and in the same way) as are members of "at-risk" communities or HIV prevention service providers.

Other potential stakeholders not explicitly included are those who pay for HIV prevention programs, or who bear the opportunity cost of investing funding in HIV prevention programs rather than some other project in the public interest. However, this group is so broad that inclusion on the community planning groups would be logistically impossible. Still, some representation of broad-based community leadership (e.g., business and church leaders) is desirable.

## 6.4.3 Perspective

The guidance's emphasis is clearly on programs designed to prevent HIV infection in the community through the use of public funds. Therefore, the implied perspective seems to be that of society as a whole.

## 6.4.4 Time Horizon

No time horizon is specified in the guidance. However, since the programs are aimed at averting HIV infection, and AIDS has a latency period of up to ten or more years, it is reasonable to infer a time horizon of at least ten years. Still, economic funding decisions made under this guidance are for a single year. Therefore, the temporal task at hand is to make current year expenditure decisions that will yield downstream benefits. Such long-range thinking is crucial to HIV prevention program planning.

## 6.4.5 Alternatives

The alternative interventions are those given in the *Guidance* (e.g., counseling, testing, referral, and partner notification; health education and risk reduction; and so on). These HIV prevention interventions are rather general and several variations of each listed intervention could be accommodated (e.g., different types of street outreach services, variants of community level interventions). Furthermore, the interventions could be delivered to any of a number of specific populations (e.g., drug users, prisoners). Additionally, HIV prevention programs consist of a portfolio of interventions; different mixtures within a portfolio could also be considered program alternatives. It is important to define intervention alternatives at a comparable level of detail (e.g., by intervention type, population, and delivery sets); this is necessary to make comparisons among them meaningful.

## 6.4.6 Attributes

The *Guidance* states that several attributes are to be considered in prioritizing HIV prevention programs: a) documented need; b) effectiveness; c) cost-effectiveness; d) behavioral or social science theoretical basis; e) "values, norms, and consumer preferences of the communities for whom the services are intended;" f) availability of other resources to provide the service; and g) other factors of local importance. We return to these attributes when discussing the decision rule below.

### 6.4.7 Relative Importance Weight

Grantees and community planning groups are free to place their own relative importance weights on the various attributes (see Table 6-1). Since the *Guidance* states that all of these attributes are to be considered, no attribute should be ignored (i.e., given a “zero” importance weighting). However, some planning groups may choose to weigh all attributes equally; other groups may choose to give special emphasis to a subset of the attributes (so long as none are ignored).

### 6.4.8 Probabilities

Priority setting is largely a process of making trade-offs among the attributes described above. The guidance gives no emphasis to determining or using the probability that a particular intervention will lead to an effect of a specified size in a given population. The *Guidance* simply notes that intervention effectiveness and cost-effectiveness can be either “demonstrated” or “probable.” Further precision in the estimation and use of probabilities may come later if and when community planning groups move toward the quantitative use of decision tree models (rather than simply relying on the core decision analytic steps), and when additional, empirical effectiveness studies are published in the literature. Although there have been clear demonstrations that one-on-one, small group and community level interventions can change high-risk behaviors, some uncertainty remains in answering the following question: Which interventions work best for whom, under what conditions, in what

settings, why, and quantitatively by how much? Further empirical work is needed to continue to refine current answers to that question; this work will help refine the probability estimates described in this decision-making step.

### 6.4.9 Decision Rule

No specific decision rule is identified in the community planning *Guidance*, so community planning groups must supply their own. The *Guidance* identifies: a) alternative programs, and b) several attributes to be considered when prioritizing programs. It does not give much emphasis to probabilistic notions. These are common characteristics of applications of multi-attribute utility theory (MAUT). MAUT applications typically involve the selection of one (or more) alternative options (out of a set of options) based on its (their) quantitative ratings on several attributes, and the relative weights assigned to the various attributes.

One (but not the only) way for community planning groups to consider all required attributes is to use a stepwise variant of MAUT, and create a user-friendly algorithm, as shown in Figure 6-1.

Such an algorithm might proceed as follows. First, the group assesses all of the documented, unmet HIV prevention needs in the community. This addresses both the attributes of documented need and the availability of other resources to provide the service. The unmet needs are ranked, ideally, according to the number of potential HIV infections that might occur in the next year without intervention. This could be done using data or expert epidemiological judgment; these data and/or expert judgment might yield estimates of numbers of potential HIV infections as well as indications of the level of uncertainty associated with those estimates. The main point is to rank order the unmet needs and, when doing so, to try to keep in mind the approximate, relative number of HIV infections at stake. (See Chapters 4 and 5.)

Second, for each unmet need, all possible interventions to address that need are listed. Third, for each possible intervention for each unmet need, the group considers whether the intervention is legal, acceptable, and accessible to the community (thereby taking into account consumer values, norms, and preferences). If any intervention is not legal, acceptable, and accessible, it is discarded. If an intervention does meet this three-part test, then the group considers the intervention further by asking whether it is: a) effective, b) cost-effective, and c) grounded in behavioral and social science theory. For every “yes” answer to these

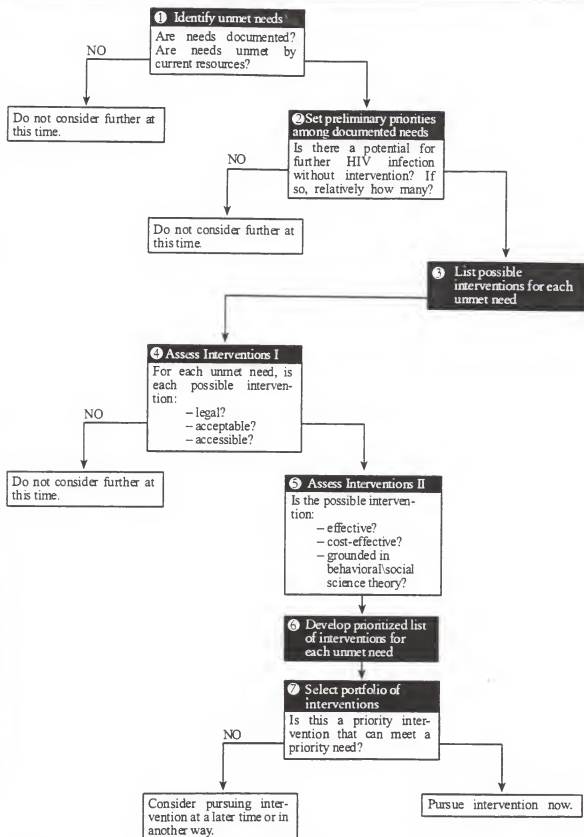
**Table 6-1: Attributes of HIV Prevention Priority Setting**

Priority setting for HIV prevention is largely a process of making trade-offs among the following attributes:

- Documented need
- Effectiveness
- Cost-effectiveness
- Behavioral/social science theoretical basis
- Community values, norms, and consumer preferences
- Availability of other resources
- Other factors of local importance



**Figure 6-1: Sample Algorithm for HIV Priority Setting**



three questions, the intervention gets a score of one point (minimum of zero; maximum of three points). If it is unclear whether a "yes" or "no" is the most appropriate answer, partial points could be awarded. The main idea here is that interventions that are theoretically-based, effective, and cost-effective are to be preferred to interventions with only one or two of these characteristics; in general, the more of these three characteristics that an intervention possesses, the better. This algorithm puts equal importance weighting on effectiveness, cost-effectiveness, and theoretical basis; although all three of these attributes should be considered, community planning groups may wish to use different relative importance weights (e.g., they may wish to make effectiveness twice as important as theoretical basis).

Having gone through this process, the community planning group has a prioritized list of unmet needs based ideally on the possible relative number of impending HIV infections (with the caveats noted above). Additionally, for each unmet need, a prioritized listing of interventions is in place. When allocating resources, the grantee should begin at the top of the unmet needs list, and for each unmet need, begin at the top of the prioritized interventions list. This process would continue until the available budget was exhausted or until all unmet needs had been addressed (whichever came first). It should be remembered that an HIV prevention program funds a portfolio of interventions to address various unmet needs, not just the single most highly rated intervention for one unmet need.

This algorithm does not give quantitative advice to the grantee as to how much to spend on each intervention in the portfolio. However, the funding of each unmet need will bear a rank-order relationship to the relative magnitude of the sub-epidemics being addressed; the algorithm also gives rank-order advice on the funding of interventions. In the future, it may be desirable to use an increasingly formal algorithm that provides more than rank-order funding advice and actually yields suggestions on approximate quantitative funding values.

#### 6.4.10 Uncertainty

A formal, quantitative MAUT application would involve varying the ratings (or scores) of alternatives on attributes, and varying the relative weights given to the attributes to determine how robust the decision was to changes in such parameter values. This technique is called sensitivity analysis and involves the

related technique of threshold (or "break-even" or "cut-point") analysis.

In the sample decision rule described above, sensitivity analysis can be employed. For example, community planning group members may disagree about whether cost-effectiveness should be given equal, or, alternatively, some portion of the weighting of effectiveness and theoretical basis. The algorithm can be "run" twice: once assuming equal importance weighting, and once assuming unequal weighting. If the relative prioritization and resource allocation for the interventions does not differ between the two runs, then the disagreement over the cost-effectiveness weighting matters little. However, if this disagreement leads to two very different results, then it must be resolved explicitly.

### 6.5 ADDITIONAL CONSIDERATIONS IN COMMUNITY PLANNING GROUP DECISION-MAKING

Priority setting in HIV prevention is an important endeavor—literally, lives are at stake. CDC has allowed for flexibility in the decision-making processes that grantees and community planning groups may use in setting priorities. However, this flexibility could also lead to confusion, and confusion can lead to conflict. One way to counter this potential for conflict is to encourage community planning groups to be explicit about their decision-making processes, and to confront explicitly areas of uncertainty and disagreement. Explicitness brings with it the benefit of being able to explore how, for instance, changes in members' relative weighting of attributes might shift prioritization and funding decisions. If, for example, disagreements over relative weighting of attributes do not shift the resulting decisions, then the disagreements can be left unresolved. If changes in relative weighting dramatically alter the resulting prioritization of programs, then the disagreements must be resolved through discussion and negotiation. Community planning groups should be especially attentive to areas of flexibility in CDC's guidance.

In the future, it may prove useful to move toward the quantitative application certain of the specific, formal decision analytic models. Some of the formal decision analytic models can provide such a decision-making process for a group of multiple stakeholders (Phillips and Phillips, 1993). Furthermore, some general software is available for use in MAUT applications (Reagan-Cirincione and Rohrbaugh,

1992). Such software can be used for a number of types of applications (including, presumably, HIV prevention program prioritization).

An important limitation of this chapter is that it does not address several key elements of decision-making in a group setting. Groups may want to explore the descriptive literature on group dynamics in decision-making (Stasser and Davis, 1981; Bazerman and Lewicki, 1983), as well as the risk communication literature on shared decision-making between communities and governmental (or industrial) organizations

(National Research Council, 1989). Chapters 2 and 3 of this book present important information on group dynamics.

HIV prevention community planning groups, and all of the persons involved with them, are important decision-makers in selecting and prioritizing HIV prevention interventions and programs. Studying, aiding, and where appropriate, providing flexible guidance for decision-making processes can yield important insights and contributions to HIV prevention efforts.

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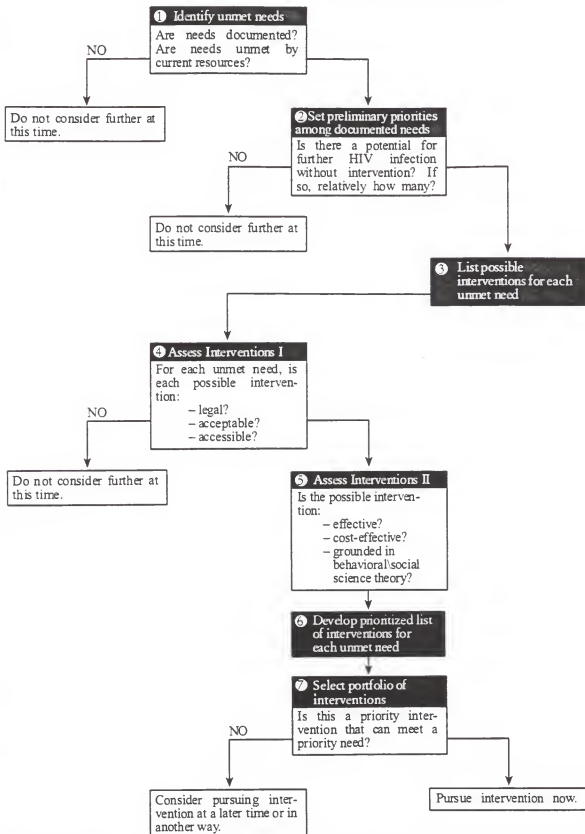


# Handouts

1. Introduction



## Sample Algorithm for HIV Priority Setting



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# Chapter 7

## Selecting Among HIV Prevention Interventions: Theoretical Basis, Effectiveness, and Cost-Effectiveness

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The Community Planning Process	Community Planning Tasks	Additional Resources
1. Ensuring Community Participation  2. Valuing and Managing the Community Planning Process  3. Conflict of Interest and Dispute Resolution	4. Developing an Epidemiologic Profile  5. Assessing and Setting Priorities for Community Needs  6. Setting Prevention Program Priorities  7. Selecting Among HIV Prevention Interventions: Theoretical Basis, Effectiveness, and Cost-Effectiveness  8. Evaluating the Community Planning Process	9. Resources for HIV Prevention Community Planning



# Chapter 7

## Selecting Among HIV Prevention Interventions: Theoretical Basis, Effectiveness, and Cost-Effectiveness

### 7.1 OVERVIEW

The *Supplemental Guidance* on HIV prevention community planning calls for grantees and community planning groups to prioritize HIV prevention interventions. Chapter 6 outlined a priority-setting process by which a community planning group can select among HIV prevention interventions. More specifically, Chapter 6 described several attributes that must be considered when prioritizing interventions and detailed how these attributes might be included in a priority-setting process. The relative weight to be given to these attributes was left up to the planning groups and grantees.

Among the attributes to be considered when prioritizing interventions are: a) the intervention's basis in behavioral and social science theory, b) its effectiveness (demonstrated or probable), and c) its cost-effectiveness (demonstrated or probable). There is a considerable body of scholarly literature on each of these attributes. This chapter provides a road-map to this literature. The majority of the information provided is contained in three appendices, one on each topic. The appendices are found at the end of the handbook.

This overview briefly describes the content of each appendix and outlines how that information might be used by grantees and community planning groups in prioritizing HIV prevention interventions. The information described in this chapter and its Appendices is more technical than the information provided elsewhere in this briefing book. Also, although there is much helpful information about effectiveness and economic evaluation in the literature, scientific judgment

must be used when applying that information to local circumstances and some scientific questions remain answered. For these reasons, it is especially important that the evaluation, behavioral, and social scientific expertise on the planning groups be involved in using this information. Where this briefing book falls short, additional technical assistance may be helpful.

### 7.2 THEORETICAL BASIS

According to the *Supplemental Guidance*, an intervention's basis in sound scientific theory is one attribute to consider in prioritizing HIV prevention interventions. Appendix A contains further information on behavioral and social science theory.

#### 7.2.1 Content

Appendix A presents a brief primer on behavioral science theory for the program planner. The appendix first describes the importance of a theoretical basis for HIV prevention interventions. Then it provides brief descriptions of several leading, behavioral and social science theories relevant to the domain of HIV prevention. These descriptions are purposely brief and should not be considered complete descriptions of any one theory. Fortunately for the practitioner, there is considerable overlap among these major theories. Thus, Appendix A presents a list of several factors common to these and other theories. Research has found that one or more of these factors must be associated with risky behavior and changed by an intervention in order for the behavior to be changed or

averted. This list was described in 1993 by the National Commission on AIDS. It should be noted that Appendix A does not contain a description of all of the many behavioral and social science theories that might be applied by planning groups as they prioritize interventions. In particular, planning groups might use theories that are more informal than those described here.

### 7.2.2. Use

The *Supplemental Guidance* calls on planning groups to consider whether or not an intervention has a behavioral/social science basis when prioritizing interventions. Sometimes community planning groups will consider interventions with clearly identified theoretical bases. For example, they may consider the relative merit of a street outreach program for injection drug users that was described in a scientific article as being grounded in the Theory of Reasoned Action.

Other times, community planning groups will consider interventions that do not have such a clearly labeled theory, but that can easily be inferred to have a theoretical basis. It is hoped that the brief descriptions of the theories and common factors provided in Appendix A will assist the community planning groups in identifying the theoretical basis of an intervention. For example, a street outreach program may not have been previously labeled as being grounded in the Theory of Reasoned Action. However, closer examination of the description of the program may reveal that one of the major components of the outreach program was designed to influence perceived social norms, one of the factors consistent with that theory.

Still other times, community planning groups will have to consider interventions whose theoretical foundations are quite unclear. It is at such times, especially, that the behavioral and social science expertise available to community planning groups will be useful in determining whether or not there is a sound theoretical basis for a certain intervention.

## 7.3 EFFECTIVENESS

The demonstrated or probable effectiveness of proposed strategies and interventions is another attribute to consider in prioritizing interventions. Further information about this attribute is provided in Appendix B.

### 7.3.1 Content

Appendix B is a paper written by CDC staff that is currently under review with a scientific journal. This paper contains a listing of some general characteristics of programs that are successful in changing or averting behaviors that put individuals at high risk for HIV infection. The paper also contains a review of studies that have tested the behavioral and/or health outcomes of HIV prevention interventions. It focuses on behaviorally-based interventions. The review is organized by intervention type (e.g., street outreach; counseling and testing). An earnest attempt was made to include all studies that tested the outcomes of behaviorally-based HIV prevention interventions (regardless of the results); of course, given the magnitude of the literature, it is certainly possible that one or more studies were missed.

### 7.3.2 Use

Grantees and community planning groups may be able to use Appendix B, the references cited therein, and their own behavioral and social science expertise to assist them in determining whether a particular HIV prevention intervention is effective (either demonstrably or probably). When considering demonstrated or probable effectiveness, it would be helpful for planning groups to define those terms explicitly. This is important because different people require different levels of evidence before considering an intervention effective. For example, some persons may be satisfied with anecdotal data, while others believe that controlled trials must be done to show effectiveness. Putting these differences on the table can be clarifying for a group process.

As sample definitions, "effectiveness" could refer to the ability of HIV prevention programs and interventions to: a) increase relevant knowledge; b) modify attitudes; c) change social norms; d) avert or reduce high-risk behaviors; and/or e) decrease HIV (and other STD) infections—depending on the stated goal of the intervention. "Demonstrated effectiveness" refers to establishing effectiveness with empirical data in carefully conducted scientific studies. Interventions with "probable effectiveness" are those supported by limited empirical data. *The theoretical basis of interventions with limited or no empirical effectiveness data should receive especially careful examination, as discussed above and in Appendix A.*

### 7.3.3 Further Guidance on Evaluation Methods.

It is important to note that Appendix B does not review methods of program evaluation. For informa-

tion about program evaluation methods, please refer to *Planning and Evaluating HIV/AIDS Prevention Programs in State and Local Health Departments: A Companion to Program Announcement #300* (CDC, 1993). This document was distributed by CDC in 1993 to all state AIDS directors. It contains the following types of information: a) definitions of key evaluation terms, b) purposes of evaluation, c) general steps in conducting evaluations, d) detailed information on process evaluation [especially, needs assessment, resource inventory, setting goals and objectives, tracking goals and objectives, referral analysis, client satisfaction, and cost analysis], and e) outcome evaluation. It also provides numerous references and resources that can be used to further understanding on any of these program evaluation topics.

Although Appendix B cites many evaluation studies, it does not review evaluation methods. Therefore, for some studies, the appendix provides little detail on the particular research methods used. Hence, if these specific citations are retrieved from the literature and reviewed, it may be helpful to ask certain questions about each study when deciding how much importance to attach to it. For example, it might be useful to evaluate the adequacy of the study design, the reliability and validity of outcome measures, the sufficiency of the sample size, and/or the generalizability of results. Windsor et al. (1994) provide a method for dissecting such evaluation studies, as do Guyatt et al. (1994).

## 7.4 COST-EFFECTIVENESS

The probable or demonstrated cost-effectiveness of an intervention is a third attribute to be considered by community planning groups in setting priorities. Appendix C provides further information on this attribute.

### 7.4.1 Content

Appendix C contains a published paper on the economic evaluation of HIV prevention and treatment service programs. The paper begins with brief descriptions of the different types of economic evaluation and provides citations for more details on these methods. It then presents one taxonomy of HIV prevention and treatment services. For each service category, all identifiable cost-benefit, cost-effectiveness or cost-utility analyses are cited. This taxonomy and accompanying reference list can be used as a road-map for locating the economic evaluations of any particular

HIV prevention service of interest. It should be noted that after that paper went to press, some other relevant analyses were presented or published. These more recent analyses are described in the "efficiency" section of the paper in Appendix B.

### 7.4.2 Use

As discussed above for "effectiveness," the *Supplemental Guidance* asks that grantees and community planning groups consider the demonstrated or probable *cost-effectiveness* of HIV prevention programs. Again, it is important for the definitions of such terms to be made explicit by the community planning groups. Definitions of the terms, "cost-effectiveness analysis," "cost-benefit analysis," and "cost-utility analysis" are given in Appendix C.

Interventions with demonstrated cost-effectiveness may be defined as those for which cost-effectiveness (or other economic evaluation) analyses have a strong empirical basis, or for which cost-effectiveness analyses yield favorable results even across a wide-range of assumptions and parameter values. Interventions with probable cost-effectiveness may be defined as those for which cost-effectiveness (or other economic evaluation) analyses have a relatively weak empirical basis, or for which the analyses yield favorable results but only under a relatively narrow set of assumptions and parameter values. The evaluation expertise available to community planning groups will be especially useful in making such determinations. *The theoretical basis of interventions with limited or no empirical effectiveness or cost-effectiveness data should receive especially careful examination, as discussed above and in Appendix A.*

## 7.5 CONCLUSION

It is hoped that this brief overview section and Appendices A, B, and C provide some useful information related to the use of the three attributes of theoretical basis, effectiveness, and cost-effectiveness in setting priorities for HIV prevention programs. Where this information falls short, further information can be had from behavioral and social science experts on the community planning groups, evaluation experts on the community planning groups, grantees who have such expertise available on staff, grantees' Project Officers, and technical assistance sources.

As noted above, the *Guidance* calls for the community planning groups to consider (among other factors) the theoretical basis, effectiveness, and cost-

effectiveness of possible interventions to address unmet needs. However, because of the nature of this material, the technical expertise on the community planning groups will be especially important in using and adapting such information from the scientific literature for local purposes. Also, in some cases, the literature may not contain all of the ideal information.

Although there have been abundant demonstrations that HIV prevention programs can change HIV-related high-risk behaviors, there are still not com-

plete answers to the question, "what mix of interventions works most effectively and efficiently for a particular population, in a given setting at a given time." Although it may be frustrating that the scientific literature does not contain all of the information that one might desire, the literature does contain numerous important studies and lessons to be learned that can be used as a scientific basis for community planning. Planning groups must use the best available scientific information to inform their planning efforts.



## 7.6 REFERENCES

Centers for Disease Control and Prevention (CDC). *Planning and Evaluating HIV/AIDS Prevention Programs in State and Local Health Departments: A Companion to Program Announcement #300*. Atlanta GA: U.S. Department of Health and Human Services, 1993.

Guyatt, G.H., Sackett, D.L., and Cook, D.J. "Users' Guides to the Medical Literature." *Journal of the American Medical Association*, 271 (1994):59-63.

Windsor, R., Baranowski, T., Clark, N., and Cutter, G. *Evaluation of Health Promotion, Health Education and Disease Prevention Programs*. Mountain View CA: Mayfield Publishing, 1994.



## Chapter 8

# Evaluating the Community Planning Process

8.1	Introduction	8-1
8.2	Evaluating the Community Planning Process	8-1
8.3	Conclusions	8-7
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The Community Planning Process	Community Planning Tasks	Additional Resources
1. Ensuring Community Participation 2. Valuing and Managing the Community Planning Process 3. Conflict of Interest and Dispute Resolution	4. Developing an Epidemiologic Profile 5. Assessing and Setting Priorities for Community Needs 6. Setting Prevention Program Priorities 7. Selecting Among HIV Prevention Interventions: Theoretical Basis, Effectiveness, and Cost-Effectiveness 8. Evaluating the Community Planning Process	9. Resources for HIV Prevention Community Planning



# Chapter 8

## Evaluating the Community Planning Process

### 8.1 INTRODUCTION

**E**valuation is a useful tool for improving and fine-tuning HIV prevention interventions. It is an on-going process that provides feedback for program planners and implementers to ensure that the intervention is being carried out as planned, as well as to indicate the extent to which the goals of the intervention are being reached. Most interventions are not all good or all bad; therefore, evaluations usually result in some combination of positive and negative feedback. A well-conducted evaluation can provide important information about which activities to continue, which to refine, which to scale back, and which to discontinue.

Prevention programs are one type of intervention. The community planning process can also be thought of as an intervention that is being carried out by each grantee. If the planning process is thought of as an intervention, then it can be evaluated, just as a specific prevention program can be evaluated. In fact, not only *can* the process be evaluated, the *Supplemental Guidance* states that it *must* be evaluated.

### 8.2 EVALUATING THE COMMUNITY PLANNING PROCESS

**T**here are three basic steps involved in evaluating the community planning process: 1) defining the goals of the evaluation; 2) completing a logic model of the planning process; and 3) creating an evaluation plan by defining program objectives and possible ways to measure them.

#### 8.2.1 Defining the Goals of the Evaluation

In the first step, the group should ask what will be gained from conducting such an evaluation? Below are three possible evaluation goals, and grantees are encouraged to add additional goals that may benefit their planning process.

### Definitions

This chapter describes three steps to follow in evaluating the community planning process. In order to carry out such an evaluation, the basic language of evaluation should be understood. The most important concepts are defined below, first as they apply to evaluating any intervention, and then as they apply specifically to the community planning process. For a thorough review of evaluation terms and concepts, readers are referred to *Planning and Evaluating HIV/AIDS Prevention Programs In State and Local Health Departments: A Companion to Program Announcement #300* (CDC, 1993).

**Evaluation goal**—Broad statement about the purpose of the evaluation; what will be gained by conducting an evaluation of the community planning process?

**Program goal**—Broad statement about the ultimate purpose of a program; what will be gained by carrying out the community planning process?

**Process objectives**—Specific activities involved in the implementation of a program in order to produce the desired results; in what specific activities must the community planning group and the grantee engage in order to reach the goals of the community planning process?

**Outcome objectives**—Specific desired outcomes of the intervention; what is the intended end result of the community planning process?

**Process evaluation**—Documentation that the intervention was carried out as planned; did the community planning process actually take place?

**Outcome evaluation**—Evidence of whether or not the intervention resulted in the intended short-term effects; were the short-term goals of the community planning process realized?

- 1) Document that the community planning process has actually taken place.
- 2) Determine whether or not the short-term program goals of community planning are being met.
- 3) Identify strengths and weaknesses of the community planning process.

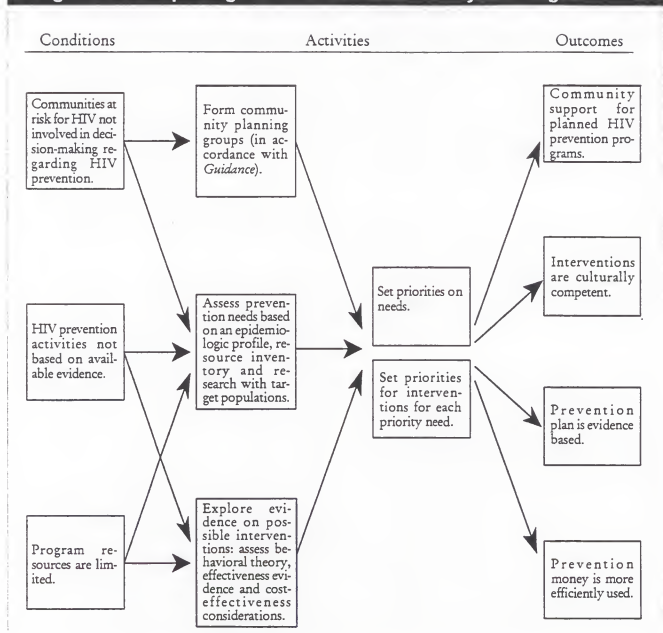
Evaluation goals address what the evaluation will produce. They are achieved through both process and outcome evaluation activities. Evaluation goals are different from program goals, which express expectations of what programmatic benefits will be derived from

implementing and engaging in the community planning process.

### 8.2.2 Completing a Logic Model

Once the goals of the evaluation are defined, the next step is to use a planning/evaluation tool called a *logic model*. In general, a logic model is a graphic representation of an intervention. In this case, the logic model will be used to represent the community planning process. The purpose of creating a logic model is to show the logical connections among the conditions that caused the group to embark on the com-

**Figure 8-1: Sample Logic Model for the Community Planning Process**



munity planning process, the activities aimed at addressing those conditions, and the outcomes that are expected to result from those activities (Linney and Wandersman, 1991). One benefit of completing a logic model is that it can help in the subsequent design of an evaluation plan.

To create a logic model, three columns are developed:

- 1) *Conditions (or problems)* - what the community planning process is designed to change, the conditions of concern;
- 2) *Activities* - components of the community planning process that will be undertaken to solve the problems; and
- 3) *Outcomes (short-term program goals)* - immediate changes anticipated as a result of the community planning process.

Once the columns of the logic model are completed, arrows are drawn to link the components of each column. Each condition should be linked to at least one activity, each activity to at least one condition and one outcome, and each outcome should be linked to at least one condition. One should be able to justify all linkages (arrows), based on knowledge from the scientific literature, program experience, or intuition. Those who are planning to implement the community planning process need to think through what problem they are trying to solve, how they hope to solve it, what they think will happen as a result of their actions, and why they think that their actions will have an effect on the conditions or problems of concern.

Figure 8-1 includes possible conditions, activities, and goals/outcomes for a community planning process logic model. Grantees should feel free to add their own ideas to each column.

### **Community Planning Process: Core Objectives for FY94 (CDC would like to assess these objectives on a nationwide basis)**

Core Objectives	Core Measures
Ensure that the nomination for community planning group membership is an open process.	Written policy specifying an open and inclusive nomination process (reported by grantees in their February 28, 1994 planning applications; please update as appropriate)
Ensure that the community planning group reflects in its composition, the characteristics of the current and projected epidemic in its jurisdiction.	Roster of community planning group members and what group(s) within the community the planning group represents (individual names need not be listed; rather the collective representation of the planning group could be profiled).
Base prioritization of needs on epidemiologic profile, resource inventory, gap analysis, and research on target populations.	Procedure for prioritizing needs.  Review of unmet needs and justification of priority needs.
Base prioritization of interventions on list of unmet needs, effectiveness, cost-effectiveness, theory, and community norms and values.	Procedure for prioritizing interventions.  Review of interventions and justification of priority interventions.
Develop the HIV prevention funding application based on the community plan.	Letters of concurrence/non-concurrence from the community planning groups (To be included in application for HIV Prevention funds P.A. #300).

**Table 8-1: Process Objectives and Measures for Community Planning Activities**

Process Objectives	Process Measures
<b>Activity 1: Form and involve the community planning group in accordance with the <i>Supplemental Guidance</i></b>	
Ensure that the nomination for community planning group membership is an open process.	Written policy specifying an open and inclusive nomination process (reported by grantees in their February 28, 1994 planning applications; please update as appropriate).
Provide community planning group members with a formal statement of their roles and responsibilities, as outlined in the <i>Guidance</i> .	Orientation plan for planning group members which includes information on their roles and responsibilities, and documentation that this orientation took place.
Create specific policies and procedures for resolving conflict within the community planning group.	Written policies and procedures for conflict and dispute resolution.
Ensure that the community planning group reflects in its composition, the characteristics of the current and projected epidemic in its jurisdiction.	Roster of community planning group members and what group(s) within the community the planning group represents (individual names need not be listed; rather the collective representation of the planning group could be profiled).
Ensure that the community planning group process is open, candid and participatory.	Written procedures for conducting meetings. Meeting attendance records. Periodic group assessments (see sample, Chapter 2)
<b>Activity 2: Assess needs</b>	
Assess the present and future extent, distribution, and impact of HIV/AIDS in the community.	Records of a completed epidemiologic profile.
Assess current HIV prevention programs in the community.	Records of a completed resources inventory.
Determine the correspondence between the needs identified and the HIV programs available in the resources inventory to identify unmet needs (gap analysis).	Records of a completed gap analysis.
Assess community opinions and values.	Records of qualitative research conducted as part of the needs assessment.
<b>Activity 3: Prioritize Unmet Needs</b>	
Ensure that setting of priorities among needs is shared among community members and organizations that administer and award HIV prevention funds.	Attendance at community planning group meetings when prioritization of needs was discussed.
Base prioritization of needs on epidemiologic profile, resource inventory, gap analysis, and research on target populations.	Procedure for prioritizing needs. Review of unmet needs and justification of priority needs.



**Table 8-1: Continued**

Process Objectives	Process Measures
<b>Activity 4: Explore Available Evidence Regarding Possible Interventions</b>	
Consider effectiveness.	<p>Review of literature demonstrating effectiveness of similar programs.</p> <p>Estimation of probable effectiveness when nothing exists in the literature and there has been no program experience to date.</p> <p>Meeting notes when effectiveness was discussed.</p>
Consider behavioral and social science theory.	<p>Review of literature on theory basis of proposed interventions.</p> <p>Meeting notes when theory was discussed.</p>
Consider cost-effectiveness.	<p>Review of literature demonstrating cost-effectiveness of similar programs.</p> <p>Estimation of probable cost-effectiveness when nothing exists in the literature and there has been no program experience to date.</p> <p>Meeting notes when cost-effectiveness was discussed.</p>
Consider prior program experience.	<p>Evidence of effectiveness and cost-effectiveness of similar programs conducted in the community that have not been published in the literature.</p> <p>Meeting notes when prior program experience was discussed.</p>
Consider community opinions.	Data regarding acceptable/appropriate HIV prevention programs.
<b>Activity 5: Prioritize Interventions</b>	
Ensure that setting of priorities among interventions is shared between community members and organizations that administer and award HIV prevention funds.	Attendance at community planning group meetings when prioritization of interventions was discussed.
Base prioritization of interventions on list of unmet needs, effectiveness, cost-effectiveness, theory, and community norms and values.	<p>Procedure for prioritizing interventions.</p> <p>Review of interventions and justification of priority interventions.</p>

### 8.2.3 Creating the Evaluation Plan

The third step in evaluating the community planning process is to create an evaluation plan by identifying process and outcome objectives, as well as ways to measure them. Both the evaluation goals and the logic model are used to form the evaluation plan.

A series of possible process and outcome objectives for the evaluation of the community planning process are discussed in Tables 8-1 and 8-2. As part of a broad plan to evaluate the community planning process from a national perspective, CDC is requesting that all grantees collect and report data on selected objectives. These are shown in the box on p. 8-3 and are presented in bold print in Tables 8-1 and 8-2 on p. 8-4 through 8-6. The development of a common core of objectives is in direct response to a request made by the grantees at the NASTAD meeting in January, 1994.

**8.2.3.1 Meeting Evaluation Goal 1.** As was discussed earlier, the first goal of the evaluation is to document that the community planning process has actually taken place as planned. To draw conclusions about the community planning process, CDC and the grantees must first be assured that it was carried out as designed. This goal is achieved through process evaluation.

The specific process objectives related to the first evaluation goal are derived from the Activities column of the logic model. Careful monitoring and documentation of these community planning activities will serve as the data for the process evaluation. Table 8-1 presents a list of the process objectives arrived at from the logic model, as well as suggested measures for each of the objectives. Again, grantees may want to incorporate additional objectives and measures that they feel are appropriate.

**8.2.3.2 Meeting Evaluation Goal 2.** The second evaluation goal is to determine whether or not the short-term program goals, or outcomes, are being met. Specific outcome objectives are derived from the Outcomes column of the logic model. Table 8-2 lists possible outcome objectives and measures for grantees to consider. Again, grantees may want to expand this list.

In order to keep all of the data from the process and outcome evaluation organized, community planning groups may find it helpful to have a Community Planning Activity Log. Such a log provides an ongoing record of every community planning activity, as well as the objective or objectives to which each activity is related. The example in the box on the next page illustrates possible entries into such a log.

**Table 8-2: Outcome Objectives and Measures for Community Planning Goals**

Outcome Objectives	Outcome Measures
Outcome 1: Ensure community support for planned HIV prevention programs	
Develop the HIV prevention funding application based on the community plan.	Letters of concurrence/non-concurrence from the community planning groups (to be included in application for HIV Prevention funds P.A. #300).
Outcome 2: Ensure that interventions in the comprehensive plan will be culturally competent	
Use input from community representatives and constituent groups to create the comprehensive plan.	Concordance between acceptable interventions, as expressed in the assessment of community values and norms, and the comprehensive plan.
Outcome 3: Base comprehensive plan on available evidence	
Base comprehensive plan on results of needs assessment and exploration of the literature.	Logic model of the comprehensive plan.
Outcome 4: Use HIV prevention funds more efficiently than in previous years	
Conduct a thorough budget analysis of funds received.	Comparison of how funds were allocated during the past year, with how they will be allocated this year.
Facilitate sharing of resources among HIV prevention providers in the community to decrease duplication of efforts.	Evidence of coordination among agencies (e.g., letters of agreement, joint programs, sharing of personnel).

8.2.3.3 Meeting Evaluation Goal 3. The third evaluation goal is to identify weaknesses and strengths in the community planning process through process and outcome evaluation. For example, if there is a process objective that most of the planning groups are having difficulty achieving, then this objective should be reconsidered. It may be that the objective is not clear enough, it is unreasonable, or more technical assistance should be provided. Grantees should record strengths and weaknesses of the community planning process as they are identified, in order to continually improve the process and build the capacity of health departments and the community to understand critical HIV prevention needs and effective ways to meet them.

### 8.3 CONCLUSIONS

This chapter has suggested that there are three steps to evaluating the community planning process: 1) defining the goals of the evaluation; 2) completing a logic model of the planning process; and 3) creating an evaluation plan by defining pro-

gram objectives and possible ways to measure them. A possible evaluation plan has been outlined in this chapter. However, grantees should design their own evaluation, tailoring the process to each locality as appropriate. In order to build a national assessment of the process, CDC has requested that a few of the process and outcome objectives be part of a core evaluation set. Of these five identified core objectives, two are already reported to CDC by grantees. Grantees may include information on the other core objectives in their quarterly progress reports or in other communication with CDC. Grantees are requested (not required) to report their progress on each of these core objectives to their CDC project officer.

The core objectives suggested here are expected to be part of a national evaluation of the community planning process. CDC is exploring options for conducting case studies, as well as an in-depth outcome evaluation. It is hoped that the combination of data reported by grantees and gathered by CDC will serve as important feedback for future years of successful community planning efforts.

**Sample Community Planning Activity Log**

Date	Activity	Participants	Objective	Supporting Documents	Comments
	Orientation for community planning group members	Community planning group members; health department staff	Provide community planning group members with a formal statement of their roles and responsibilities as outlined in the <i>Guidance</i>	Statement of roles and responsibilities for new members; minutes of meeting stating that all members were given a copy of above document	
	Community planning group priority-setting meeting on needs	Community planning group members	Ensure that priority setting of needs is shared between organizations that administer and award HIV prevention funds and community members; and base prioritization of needs on epidemiologic profile	Attendance sheet; prioritization model; list of prioritized unmet needs	

## 8.4 REFERENCES

Centers for Disease Control and Prevention (CDC). *Planning and Evaluating HIV/AIDS Prevention Programs in State and Local Health Departments: A Companion to Program Announcement #300*. Atlanta GA: U.S. Department of Health and Human Services, 1993.

Francisco, V. T., Paine, A. L., and Fawcett, S. B. "A Methodology for Monitoring and Evaluation of Community Health Coalitions". *Health Education Research*, 8 (1993):417-432.

Goodman, R. M. and Wandersman, A. "FORECAST: A Formative Approach to Evaluating Community Coalitions and Community Based Initiatives". To be published in Kaftarian, S. and Hanson, W. (eds.), *Improving Methodologies for Evaluating Community-based Partnerships for Preventing Alcohol, Tobacco, and Other Drug Use*. Journal of Community Psychology, 1994.

Linney, J. A. and Wandersman, A. *Prevention Plus III: Assessing Alcohol and Other Drug Prevention Programs at the School and Community Level*. Written for Substance Abuse Prevention. Washington DC: Department of Health and Human Services, 1991.

## Chapter 9

### Resources

CDC Contacts

~~NASTAD Membership Directory~~

Other CDC Funded HIV Prevention Resources

Other Resources for Community Planning

The Community Planning Process	Community Planning Tasks	Additional Resources
<ol style="list-style-type: none"><li>1. Ensuring Community Participation</li><li>2. Valuing and Managing the Community Planning Process</li><li>3. Conflict of Interest and Dispute Resolution</li></ol>	<ol style="list-style-type: none"><li>4. Developing an Epidemiologic Profile</li><li>5. Assessing and Setting Priorities for Community Needs</li><li>6. Setting Prevention Program Priorities</li><li>7. Selecting Among HIV Prevention Interventions: Theoretical Basis, Effectiveness, and Cost-Effectiveness</li><li>8. Evaluating the Community Planning Process</li></ol>	<ol style="list-style-type: none"><li>9. Resources for HIV Prevention Community Planning</li></ol>



## Chapter 9

### Resources

#### OVERVIEW

This section of the handbook lists a variety of resources that might be useful to project areas and members of the community planning body in HIV prevention planning. A copy of the *Supplemental Guidance on HIV Prevention Community Planning* is included, along with the following resource listings:

#### CDC Contacts

- National Center for Prevention Services: DSTD/HIVP Project Officers by region and project area.
- National Center for Infectious Diseases: Division of HIV/AIDS liaisons to state and local HIV surveillance and serosurveillance programs.

#### ~~NASTAD Membership Directory~~

#### Other CDC Funded HIV Prevention Resources

- American Red Cross statewide HIV/AIDS Network Coordinators.
- National minority organizations with CDC cooperative agreements for HIV/STD preventions.
- The United States Conference of Mayors HIV/AIDS grantees.

#### Other Resources for Community Planning

- Resource organizations for dispute resolution.
- State coordinators for the Planned Approach to Community Health (PATCH) program.

## Chapter 2 References

References are listed in the following order: books, journal articles, and other sources. The references are listed in alphabetical order of the author's name. The references are listed in the following order: books, journal articles, and other sources. The references are listed in alphabetical order of the author's name.

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References are listed in the following order: books, journal articles, and other sources. The references are listed in alphabetical order of the author's name. The references are listed in the following order: books, journal articles, and other sources. The references are listed in alphabetical order of the author's name.



## CDC Contacts

CDC Reports

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Program Operations Branch, DSTD/HIVP  
Field Operations Section**

March 1, 1994

**Gary R. West, Acting Chief**  
Phone # (404) 639-8315

PROJECT AREA	PROJECT OFFICER		PROJECT AREA	PROJECT OFFICER	
	STD/HIV	CBO		STD/HIV	CBO
<b>REGION 1</b>	<b>DILLON, SECTION CHIEF</b>		<b>REGION 6</b>	<b>FIKES, SECTION CHIEF</b>	
CONNECTICUT MAINE MASSACHUSETTS NEW HAMPSHIRE RHODE ISLAND VERMONT	CYLAR TULLIER CYLAR CYLAR BLANCATO TULLIER	LOPEZ  DIAZ-KENNEY	ARKANSAS LOUISIANA NEW MEXICO (IHS) OKLAHOMA TEXAS HOUSTON	SALONE FOLLAS BURNETT BURNETT MARTICH MARTICH	FOLEY  FOLEY FOLEY
<b>REGION 2</b>	<b>DILLON, SECTION CHIEF</b>		<b>REGION 7</b>	<b>QUINN, SECTION CHIEF</b>	
NEW JERSEY NEW YORK STATE NEW YORK CITY PUERTO RICO VIRGIN ISLANDS	BLANCATO TULLIER TULLIER CYLAR CYLAR	BLANCATO  GRAHAM/LOPEZ DIAZ-KENNEY	IOWA KANSAS MISSOURI NEBRASKA	ADAMS-RIVERS ADAMS-RIVERS ADAMS-RIVERS ADAMS-RIVERS	
<b>REGION 3</b>	<b>PINCKNEY, SECTION CHIEF</b>		<b>REGION 8</b>	<b>QUINN, SECTION CHIEF</b>	
DELAWARE DIST. OF COLUMBIA MARYLAND BALTIMORE PENNSYLVANIA PHILADELPHIA VIRGINIA WEST VIRGINIA	PACK HALE SCHWARZ SCHWARZ SCHWARZ SCHWARZ PACK PACK	BROWN-BRYANT  BROWN-BRYANT  BROWN-BRYANT	COLORADO MONTANA NORTH DAKOTA SOUTH DAKOTA UTAH WYOMING	FARRELL FARRELL FARRELL FARRELL FARRELL FARRELL	TAVERAS   GLOVER
<b>REGION 4</b>	<b>FIKES, SECTION CHIEF</b>		<b>REGION 9</b>	<b>QUINN, SECTION CHIEF</b>	
ALABAMA FLORIDA GEORGIA KENTUCKY MISSISSIPPI NORTH CAROLINA SOUTH CAROLINA TENNESSEE	SALONE MARTICH FOLLAS SALONE SALONE FOLLAS MARTICH MARTICH	FOLEY FOLEY  FOLLAS	ARIZONA CALIFORNIA ANAHEIM CAKLAND SAN DIEGO SAN JOSE SANTA BARBARA LOS ANGELES SAN FRANCISCO GUAM HAWAII MICRONESIA MARSHALL IS. NEVADA NO. MARIANA PALAU SAMOA	WILLIAMS FARRELL     WILLIAMS ADAMS-RIVERS WILLIAMS WILLIAMS ADAMS-RIVERS ADAMS-RIVERS WILLIAMS ADAMS-RIVERS WILLIAMS WILLIAMS	DEGROFF  GLOVER TAVERAS TAVERAS GLOVER GLOVER GLOVER DEGROFF  TAVERAS
<b>REGION 5</b>	<b>PINCKNEY, SECTION CHIEF</b>		<b>REGION 10</b>	<b>DILLON, SECTION CHIEF</b>	
ILLINOIS CHICAGO INDIANA MICHIGAN MINNESOTA OHIO WISCONSIN	MIDDLEKAUFF MIDDLEKAUFF PACK PACK MIDDLEKAUFF SCHWARZ SCHWARZ	HALE  BROWN-BRYANT BROWN-BRYANT SCHWARZ HALE	ALASKA IDAHO OREGON WASHINGTON	BLANCATO BLANCATO BLANCATO BLANCATO	BLANCATO   BLANCATO

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WALTER CHOW  
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Earl Handwerker	Region VII: Iowa, Kansas, Missouri, and Nebraska
Donald Ruberti	Region III: Delaware, Maryland, Pennsylvania, Philadelphia, Virginia, and West Virginia  Region VI: Louisiana
Ron Sanders	Region III: District of Columbia  Region V: Illinois, Chicago, Indiana, Michigan, Minnesota, Ohio, and Wisconsin
Mike Skaggs	Region IV: Alabama, Florida, Georgia, Kentucky, Mississippi, North Carolina, South Carolina, and Tennessee  Region VI: Texas and Houston
Steven Sloane	Region I: Connecticut, Maine, Massachusetts, New Hampshire, Rhode Island, and Vermont  Region II: New Jersey, New York, and New York City
Dena Wells	Region II: Puerto Rico and Virgin Islands  Region VIII: Colorado, Montana, North Dakota, South Dakota, Utah, and Wyoming  Region X: Alaska, Idaho, Oregon, and Washington

Other CDC Funded HIV  
Prevention Resources

Other CDC Funded HIV  
Prevention Resources



## AMERICAN RED CROSS OFFICE OF HIV/AIDS EDUCATION FUNCTION AREAS

In 1988, the CDC cooperative agreement with the American Red Cross identified seven programmatic areas (Core, Hispanic, African American, Workplace, Youth, International, and Blood) and established a framework that centers on the nationwide delivery of standardized HIV/AIDS training and educational presentations and the development and distribution of HIV/AIDS educational materials. Four instructional programs have been developed to reach specialized audiences: Workplace, African American, Hispanic, and General Community. Each of the instructional programs has an emphasis on Youth and new materials will continue to expand and strengthen this focus. Additionally, International and Blood education are incorporated in the various instructional areas.

Within the programmatic areas are the following functional areas:

### Training

Red Cross has a three-tiered system for training instructors in the four program areas. National faculty are established in the initial implementation of a program. They in turn, train people to be "instructor trainers." The instructor trainers train people to be "instructors." Instructors are individuals who must pass a standardized training, and assessment process to be certified to present Red Cross programs. Youth-related content is incorporated into all of the programs. Most of the people trained are volunteers.

### Evaluation

Impact evaluation indicators and measures were developed for the Workplace, Hispanic, General Community, and African American programs. These indicators reflect the information, psycho-social components, personal beliefs, attitudes and behavioral intentions that must be measured to know whether or not these programs are having the intended impact. Specific surveys and methods are in development to standardized the measurement of these indicators for a full scale impact evaluation in 1994. The following are key Red Cross evaluation activities:

**Chapter labs:** Five chapters are currently funded to conduct in-depth, quasi-experimental studies to measure impact of Red Cross programs.

**Federal Training Initiative:** Special workplace evaluation is being conducted with federal agencies receiving Red Cross training. This is occurring in a variety of sites around the country.

**Technical assistance:** Chapters, CBOs, and health departments are provided assistance with developing research designs and data analysis. A "how to" document on basic process and impact evaluation designs was written and widely distributed.

**Surveys:** Chapter and instructor surveys are administered yearly. Statewide networks report on activities quarterly.

**Needs assessments:** Special targeted needs assessments for youth and caregivers of people living with HIV were conducted in 1992. They have guided ongoing development and enhancement of existing programs.

The Red Cross also utilizes a strategic planning process, including an external review of the overall program, to set corporate-wide direction and renewal of the Cooperative Agreement with CDC.

## Marketing

Marketing of Red Cross HIV/AIDS education to internal and external audiences (chapters, CBOs, government agencies, schools, colleges, religious institutions, etc.) is aimed at continuing and expanding active chapter participation in HIV/AIDS programs and services and increasing usage by the American public of Red Cross programs. Special emphasis is placed on reaching culturally diverse populations and the workforce.

A wide range of marketing activities are ongoing and include: development of specific tools for use at the local, state, and national Red Cross levels; congressional briefing packets for chapter use; timely communication via monthly newsletter and satellite programs; promotional activities and materials for special audiences; and marketing kits for chapters.

Red Cross works with a marketing contractor to design strategies and materials for the General Community, African American, Workplace, and Hispanic programs.

## Grants/Capacity building

Competitive grants are awarded to chapters for providing HIV/AIDS education through creative and collaborative educational approaches and creative outreach strategies to individuals identified as hard-to-reach and/or high-risk behavior category. For the 1994 calendar year, \$775,000 has been awarded to chapters who applied for "outreach grants", and another twenty-seven chapters received mini-grants totalling \$85,415.

The Statewide HIV/AIDS Networks Program was developed to enhance communication and cooperation in sharing Red Cross HIV/AIDS information and resources on a statewide basis among Red Cross field units and selected public and private HIV/AIDS organizations, particularly state and local health departments and departments of education. In 1994, 43 statewide networks covering 45 states have been funded in amounts ranging from \$5,000 to \$60,000.

## Collaborations

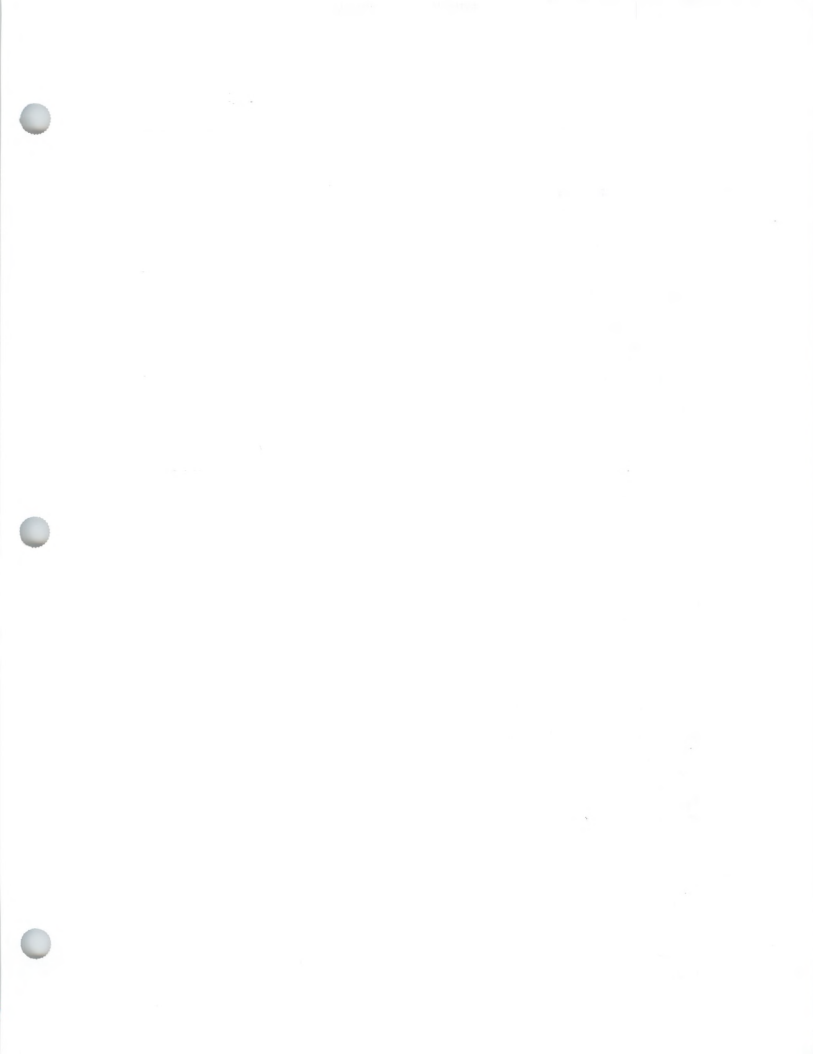
To expand the reach of Red Cross programs, national collaborations with other organizations have occurred on a time-limited or ongoing basis. Types of collaborative relations include: supporting regional conferences for Hispanic Designers Incorporated, production with the National Urban League of an HIV/AIDS training module for African Americans, endorsement of Red Cross Hispanic program by National Council of La Raza for use by their affiliates, provision of HIV/AIDS track at national conference of Camp Fire Boys and Girls, and with the Boys and Girls Clubs of America, the development of age-appropriate HIV/AIDS curriculum for out-of-school youth ages 6 through 16.

The Red Cross also collaborates with National Partners, CDC, and others in the production and promotion of the Red Cross monthly satellite program, "CrossLink." Partnerships are a regular feature of Numbered Notices (newsletters) to Red Cross units.

Red Cross national-level collaborations often result in similar collaborations by chapters. A requirement for awarding of both chapter and statewide network grants is collaboration with local and/or state organizations. Collaboration is a key part of *all* Red Cross chapter activities.

## Materials Development/Distribution

A staff of education and technical information specialists at Red Cross work with an advisory group of HIV/AIDS experts to develop training programs and related materials. Staff also depend on needs assessments, focus groups, chapter site visits, chapter feedback, and CDC reviews to guide the development and updating of materials. Program materials are reviewed annually and revised every three years. The Second Edition of the General Community HIV/AIDS program will maintain a focus on facts-based, non-judgmental, culturally-sensitive HIV/AIDS education. New educational methods include skills-based modules in the areas of decision-making, use of condoms, and postponement of sex.



**NATIONAL MINORITY ORGANIZATIONS WITH CDC COOPERATIVE AGREEMENTS  
PROGRAM ANNOUNCEMENT NUMBER 305**

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## NATIONAL/REGIONAL MINORITY ORGANIZATIONS WITH CDC COOPERATIVE AGREEMENTS PROGRAM ANNOUNCEMENT 305A

Program Announcement 305A provided supplemental funds to five National/Regional Minority Organizations (NRMO) to provide technical assistance and training to community planning groups and the state and local health departments working with them to facilitate representation, inclusiveness, and parity in the implementation of HIV prevention community planning. The five NRMOs funded under this program announcement are shown below, and their regional designations are shown on the following page.

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Note: To access these technical assistance resources, call the CDC, Division of STD/HIV Prevention Project Officer for your jurisdiction.



## NATIONAL/REGIONAL MINORITY ORGANIZATIONS: PROGRAM ANNOUNCEMENT 305A REGIONAL LEAD RESPONSIBILITY

Note: Each region of the country has been assigned a "lead" Program Announcement 305A NRMO. The role of this lead organization is to be the principle PIR (parity, inclusion and representation) liaison with CDC in providing technical assistance to state and local health departments and community planning groups in HIV prevention community planning.

Region I: NMAC; co-lead NOBCO.

Connecticut, Maine, Massachusetts, New Hampshire, Rhode Island, Vermont.

Region II: NCLR; co-lead NMAC.

New Jersey, New York, Puerto Rico, Virgin Islands, New York City.

Region III: NMAC; co-lead NOBCO.

Delaware, D.C., Maryland, Pennsylvania, Virginia, West Virginia, Philadelphia.

Region IV: NOBCO; co-lead NCLR.

Alabama, Florida, Georgia, Kentucky, Mississippi, North Carolina, South Carolina, Tennessee.

Region V: NOBCO; co-lead NCLR.

Illinois, Indiana, Michigan, Minnesota, Ohio, Wisconsin, Chicago.

Region VI: NNAAPC; co-lead USBHA.

Arkansas, Louisiana, New Mexico, Oklahoma, Texas.

Region VII: USBHA; co-lead NNAAPC.

Kansas, Missouri, Nebraska, Iowa.

Region VIII: USBHA; co-lead NNAAPC.

Colorado, Montana, North Dakota, South Dakota, Utah, Wyoming.

Region IX: NCLR; co-lead NMAC.

American Samoa, Arizona, California, Guam, Hawaii, Los Angeles, Nevada, Marshall Islands, Micronesia, N. Mariana, Palau, San Francisco.

Region X: NNAAPC; co-lead USBHA.

Alaska, Idaho, Oregon, Washington.

## THE UNITED STATES CONFERENCE OF MAYORS HIV/AIDS PROGRAM

The U.S. Conference of Mayors (USCM), through its Collaborative HIV/AIDS Prevention Grants Program, has been issuing grants for local community-wide needs assessment and prevention planning projects focusing on the needs of gay and bisexual men of color, as well as substance users, women, and youth at high risk with special emphasis on racial and ethnic minorities. These projects, initiated in March of 1993, have developed a variety of planning tools and strategies that may be useful for those in the process of developing needs assessment instruments (e.g., KABs, focus group protocols, interview formats, provider surveys) or interested in prevention planning structures, priority setting and consensus building strategies, and ways to enhance inclusion and representation.

The Prevention Intervention Grants described below may also be of interest to those seeking information on potential strategies to increase accessibility among certain populations.

In April 1994, USCM will release new grants for local HIV prevention needs assessment projects and for implementation of HIV interventions targeting gay and bisexual men of color.

For information on these grants and resources for HIV Prevention Community Planning, please contact Richard C. Johnson or Mara T. Paternaster at 202/293-7330.

## COLLABORATIVE HIV/AIDS PREVENTION GRANTS PROGRAM

Boston Department of Health and Hospitals is conducting a community-wide assessment of HIV education and prevention services using KAB surveys, focus groups, and key informant interviews specially developed for the African American and Latino/a, Haitian and Portuguese communities, including women, youth and injection drug users. Contact: Anibal Sosa, (617) 534-4559.

Milwaukee Indian Health Board, Inc. is conducting an assessment focusing on the education and prevention needs of gay/bisexual men, youth in high risk situations, substance abusers and women. KAB and provider surveys and one-on-one interviews with members of each of the four target populations have been the primary methods used. Contact: Joan Lawrence, (414) 931-8111.

Northern Virginia Planning District Commission, working with the Northern Virginia HIV Consortium, implements a collaboration between five health departments and nine community-based organizations. It has primarily employed KAB surveys and provider interviews to examine the availability and utilization of existing prevention services and access to those services. Contact: Callie B. Gass, (703)642-0700.

Wake County Department of Health, through its "Partners in Prevention" project, has brought together the county department of health and three community-based organizations to design and implement a community-wide HIV prevention assessment using surveys, interviews and focus groups. Contact: Gibbie Harris, (919) 250-4516.

Lucas County District Board of Health, a collaboration between the Lucas County and Toledo health departments and the agencies within the Toledo/Lucas County AIDS Program, is focused on examining the availability and need for prevention services with emphasis on assessing existing service capacity, barriers to utilization of existing services and gaps in service availability. Contact: Dan Rutt, (419) 245-4120.

## HIV/AIDS PREVENTION INTERVENTION GRANTS

Kansas City Missouri Health Department is using a three-tier approach involving street outreach, group and individual counseling, and referral into testing/counseling and case management services, to target young gay and bisexual males. Contact: Judy Moore-Nichols (816) 923-2300

Asian and Pacific Islander Coalition on HIV/AIDS, in collaboration with the New York City Department of Health, is providing HIV prevention case management, one-on-one client support, and volunteer recruitment and coordination for mono-/bilingual Asian and Pacific Islander gay/bisexual men. Contact: John Manzoni, (212)349-8155.

City of Plainfield/Plainfield Health Division has a project aimed at women who receive services from the city of Plainfield, and employs culturally sensitive education materials to dispel misinformation and negative attitudes, beliefs, and concerns regarding symptoms of AIDS, safer sex practices, etc. Contact: Ruby Hodge, (908)753-3084.

San Bernardino County Department of Public Health, in collaboration with two community-based organizations, has developed and implemented a two-tiered community outreach project targeting African American gay/bisexual men, injection drug users and women. Contact: Alexander Taylor, (714) 383-3065.

PR CONCRA has integrated a new prevention service component into existing clinical services for HIV-positive individuals through the design of workshop and support group curricula intended to increase access to risk reduction services for gay and bisexual men and persons with HIV. Contact: Rafael Pagan, (809)753-9443

## PUBLICATIONS

USCM publishes reports and case studies on a variety of topics, some of which are particularly relevant to the HIV prevention planning process. Suggested publications include: *Needs Assessments for HIV Prevention Services*, *Evaluation for HIV Prevention Projects*, *Assessing the HIV-Prevention Needs of Gay and Bisexual Men of Color*, *Working Together: The Austin/Travis County HIV Commission*, *TB and HIV*, and others.

For a complete list of publications and ordering, write to HIV/AIDS Publications, The United States Conference of Mayors, 1620 Eye Street, N.W., Washington, D.C. 20006; or fax your request to: 202/429-0422.

THE UNIVERSITY OF CHICAGO  
DEPARTMENT OF THE HISTORY OF ARTS  
1100 EAST 58TH STREET  
CHICAGO, ILLINOIS 60637

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CHICAGO, ILLINOIS 60637

## Other Resources for Community Planning

Other Resources for  
Community Planning

## RESOURCE ORGANIZATIONS FOR DISPUTE RESOLUTION

### **Administrative Conference of the United States (ACUS)**

2120 L Street, NW, Suite 500  
Washington, DC 20037  
(202) 254-7020

### **American Arbitration Association**

140 West 51st St.  
New York, NY 10020  
(212) 484-4000

### **The American Bar Association**

Section on Dispute Resolution  
1800 M Street, NW, Suite 200  
Washington, DC 20036  
(202) 331-2258

### **Community Relations Service**

5550 Friendship Blvd. Suite 330  
Chevy Chase, MD 20815  
(301) 492-5959

### **Consortium on Peace Research, Education, and Development (COPRED)**

George Mason University  
Fairfax, VA 22030  
(703) 993-3639

### **Institute for Conflict Analysis and Resolution**

George Mason University  
Fairfax, VA 22030-4444  
(703) 993-1300

### **Institute for Multi-Track Diplomacy**

1133 20th St., NW #321  
Washington, DC 20036  
(202) 466-4605

### **International Society for Intercultural Education, Training, and Research**

Georgetown University  
733 15th St., NW, Suite 900  
Washington, DC 20005  
(202) 466-7883

### **National Coalition Building Institute**

1835 K St., NW  
Washington, DC 20006  
(202) 785-9400

**National Institute for Dispute Resolution**

1901 L Street, NW, Suite 600  
Washington, DC 20036  
(202) 466-4764

**Program for Community Problem Solving**

915 15th St., NW, Suite 600  
Washington, DC 20005  
(202) 783-2961

**Project Victory**

1621 Connecticut Ave., NW #201  
Washington, DC 20009(  
202) 483-9290  
OR:  
560 Oxford Ave. #1  
Palo Alto, CA 94306  
(415) 424-9622

**Society of Professionals in Dispute Resolution (SPIDR)**

815 15th St, NW, Suite 530  
Washington, DC 20005  
(202) 783-7277



## STATE COORDINATORS

### PLANNED APPROACH TO COMMUNITY HEALTH (PATCH)

PATCH, the acronym for Planned Approach to Community Health, is a cooperative program of technical assistance managed and supported by the Centers for Disease Control (CDC). PATCH is designed to strengthen state and local health departments' capacities to plan, implement, and evaluate community-based health promotion activities targeted toward priority health problems.

#### Alabama

Jim McVay  
Alabama Department of Public Health  
206 State Office Building  
Montgomery, AL 36130  
(205) 242-5095

#### Alaska

Glen Ray  
Division of Public Health  
Department of Health and Social Services  
P. O. Box 199610  
Juneau, AK 99811-0610  
(907) 465-3140

#### Arizona

Becky Tucker  
Office of Health Promotion & Education  
Arizona Department of Health Services  
3008 North Third Street  
Phoenix, AZ 85012  
(602) 230-5941

#### Arkansas

Carla Gilbreath  
Arkansas State Department of Health  
4815 W. Markham Street  
Little Rock, AR 72205-3876  
(501) 661-2747

#### California

Barbara Marquez  
Health Promotion Section  
California Department of Health Services  
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P.O. Box 942732  
Sacramento, CA 94234-7320  
(916) 322-6868

Connecticut

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Department of Health and Addiction Services  
150 Washington Street  
Hartford, CT 06106  
(203) 566-7867

Delaware

Fred N. Breukelman  
Center for Health Promotion & Education  
Division of Public Health  
P.O. Box 637  
Dover, DE 19903  
(302) 739-4724

District of Columbia

Marcia Timoll  
Office of Health Promotion  
Commission of Public Health  
1660 L. Street, NW  
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Washington, DC 20036  
(202) 673-6738

Rosemarie McClaren  
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Florida

Jennie Hefelfinger  
Health & Rehabilitative Services  
Preventive Health Services  
1317 Winewood Blvd.  
Bldg. A, Room 201-HSH  
Tallahassee, FL 32399-0700  
(904) 487-3220

Georgia

Haydee Bundshuh  
Community Wellness/Health Promotion  
Georgia Department of Human Resources  
Division of Public Health  
878 Peachtree St., NE, Room 102  
Atlanta, GA 30309  
(404) 657-6649

## Illinois

R. Stephen Knobloch  
Division of Health Promotion  
Illinois Department of Public Health  
535 West Jefferson  
Springfield, IL 62761  
(217) 785-2060

## Indiana

Ray Guest  
Division of Health Education  
Indiana State Department of Health  
1330 W. Michigan Street  
P.O. Box 1964  
Indianapolis, IN 46206-1964  
(317) 633-0268

## Iowa

Lorrie Graaf  
Bureau of Health Promotion  
Iowa Department of Health  
Lucas State Office Building  
Des Moines, IA 50319-0075  
(515) 281-7739

## Kansas

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Landon State Office Building  
900 S.W. Jackson Street  
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Topeka, KS 66612-1290  
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State House, Station 11  
Augusta, ME 04333  
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## Oklahoma

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## South Carolina

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#### Virgin Islands

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St. Croix, V.I. 00823  
(809) 773-1311 ext. 3143 or 3144

Ulalie Smith  
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#### Wyoming

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Cheyenne, WY 82002  
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## Supplemental Guidance

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**SUPPLEMENTAL GUIDANCE ON HIV PREVENTION  
COMMUNITY PLANNING FOR NONCOMPETING  
CONTINUATION OF COOPERATIVE AGREEMENTS FOR  
HIV PREVENTION PROJECTS**

**INTRODUCTION**

This guidance is offered to assist state and local health department HIV Prevention Cooperative Agreement grantees (referred to in subsequent portions of this document as "Grantees") in the preparation of plans to undertake HIV Prevention Community Planning in fiscal year (FY) 1994 and subsequent fiscal years. The Centers for Disease Control and Prevention (CDC) will award approximately \$12,000,000 in new funds for the FY 1994 planning process through the HIV Prevention Cooperative Agreements with state, territorial, and local health departments on or about January 15, 1994. These funds will be used to establish plans for the use of HIV prevention resources awarded under program announcement #300 (Cooperative Agreement for Human Immunodeficiency Virus [HIV], Prevention Projects Program Announcement and Availability of Funds for Fiscal Year 1993).

**A. ESSENTIAL COMPONENTS OF A COMPREHENSIVE HIV PREVENTION PROGRAM**

Participatory community planning is an essential component of effective HIV prevention programs. This type of planning is evidence-based (i.e., based on HIV/AIDS epidemiologic surveillance and other data, ongoing program experience, program evaluation, and a comprehensive, objective needs assessment process) and incorporates the views and perspectives of the groups at risk for HIV infection/transmission for whom the programs are intended, as well as the providers of HIV prevention services. In addition to community planning, the other essential components of a comprehensive HIV prevention program are (also see program announcement #300):

1. Epidemiologic and behavioral surveillance and research and collection of other health and demographic data to monitor the HIV/AIDS epidemic and behaviors/practices that facilitate HIV transmission and to project trends in the epidemic;
2. HIV counseling, testing, referral, and partner notification (CTRPN) to provide, consistent with state laws, both anonymous and confidential client-centered opportunities for individuals to learn their serostatus and to receive prevention counseling and referral to other preventive, medical, and social services;
3. Individual level interventions (e.g., prevention case management) that provide ongoing health education and risk-reduction counseling, assist clients in making plans for individual behavior change and ongoing appraisals of their own

behavior, facilitate linkages to services in both clinic and community settings (e.g., substance abuse treatment settings) in support of behaviors and practices which prevent transmission of HIV, and to help clients make plans to obtain these services;

4. Health education and risk-reduction interventions for groups to provide peer education and support, as well as to promote and reinforce safer behaviors and provide interpersonal skills training in negotiating and sustaining appropriate behavior change;
5. Community level interventions for populations at risk for HIV infection that seek to reduce risk behaviors by changing attitudes, norms, and practices through health communications, social (prevention) marketing, community mobilization/organization, and community-wide events;
6. Public information programs for the general public that seek to dispel myths about HIV transmission, support volunteerism for HIV prevention programs, reduce discrimination toward individuals with HIV/AIDS, and promote support for strategies and interventions that contribute to HIV prevention in the community;
7. Evaluation and research activities necessary to conduct formative, process, and outcome evaluations of HIV prevention programs and to assess the cost-effectiveness and cost-benefits of strategies and interventions; and
8. HIV prevention capacity-building activities, such as strengthening governmental and nongovernmental public health infrastructure in support of HIV prevention, implementing systems to ensure the quality of services delivered, and improving the ability to assess community needs and provide technical assistance in all aspects of program planning and operations.

## B. DEFINITION OF HIV PREVENTION COMMUNITY PLANNING

HIV Prevention Community Planning refers to an ongoing process whereby grantees share responsibilities for developing a comprehensive HIV prevention plan with other state/local agencies, nongovernmental organizations, and representatives of communities and groups at risk for HIV infection or already infected. Priority setting accomplished through a participatory process will result in programs that are responsive to high priority, community-validated needs within defined populations. HIV prevention programs developed without community collaboration are unlikely to be successful in preventing the transmission of HIV infection or in garnering the necessary public support for effective implementation. Persons at risk for HIV infection and persons with HIV infection should play a key role in identifying prevention needs not adequately being met by existing

programs and in planning for needed services that are culturally appropriate. The necessary steps of HIV Prevention Community Planning are:

1. Assessing the present and future extent, distribution, and impact of HIV/AIDS in defined populations in the community;
2. Assessing existing community resources for HIV prevention to determine the community's capability to respond to the epidemic. These resources should include fiscal, personnel, and program resources, as well as support from public (Federal, state, county, municipal), private, and volunteer sources. This assessment should identify all HIV prevention programs and activities according to defined high risk populations;
3. Identifying unmet HIV prevention needs within defined populations;
4. Defining the potential impact of specific strategies and interventions to prevent new HIV infections in defined populations;
5. Prioritizing HIV prevention needs by defined high risk populations and by specific strategies and interventions;
6. Developing a Comprehensive HIV Prevention Plan consistent with the high priority HIV prevention needs identified through the HIV Prevention Community Planning process; and
7. Evaluating the effectiveness of the planning process.

The grantee will develop an application for CDC FY 1995 (and beyond) funding based on the Comprehensive HIV Prevention Plan.

#### C. ELEMENTS OF A COMPREHENSIVE HIV PREVENTION PLAN

The necessary elements of a comprehensive HIV prevention plan include the following:

1. An HIV/AIDS epidemiologic profile that reflects the current and future epidemic in that jurisdiction (e.g., reported AIDS cases, projected AIDS cases, estimated HIV prevalence in defined populations, HIV incidence, HIV risk behaviors, and other information, such as sexually transmitted diseases (STDs), teen pregnancy, and drug use, needed to target and monitor HIV prevention efforts).
2. A description of target populations to be reached by primary HIV prevention interventions (i.e., by age group, gender, race/ethnicity, socioeconomic status,

geographic area, sexual orientation, exposure category, primary language, and significant cultural factors) and unmet needs and barriers in reaching populations.

3. A description of priority individual-, group-, and community-level strategies and interventions that are culturally and linguistically appropriate for defined target populations whose serostatus is unknown, negative, or positive. These strategies and interventions include HIV counseling, testing, referral, and partner notification; prevention case management and other one-on-one risk reduction prevention programs; peer education programs for high-risk populations; school-based programs; community mobilization; and health communications and social (prevention) marketing approaches. Both existing and proposed interventions should be described.
4. A description of how primary HIV prevention activities are linked to secondary HIV prevention activities, i.e., activities to prevent or delay the onset of illness in persons with HIV infection.
5. Goals and measurable objectives that are programmatically meaningful for HIV prevention in defined populations. These goals and objectives should be developed for both the short-term (budget period) and the long-term (project period).
6. A description of other HIV prevention-related activities (e.g., epidemiologic and behavioral surveillance, research, and program evaluation activities) and how these are linked to HIV and other prevention program strategies in the geographic area for which the plan is developed.
7. A description of how public and nongovernmental agencies will coordinate within the area for which the plan is developed to provide HIV prevention services and programs.
8. An HIV prevention technical assistance plan identifying needs of grantees and community-based providers in the areas of program planning, implementation, and evaluation.
9. An evaluation plan for the HIV prevention planning process as delineated in Item 13 of Section D.

#### D. PRINCIPLES OF HIV PREVENTION COMMUNITY PLANNING

State health departments are responsible for the health of the populations in their jurisdictions. States have a broad responsibility in surveillance, prevention, overall planning, coordination, administration, fiscal management, and provision of essential

public health services. States recognize, however, that governmental agencies alone are limited in their scope and ability to solve complex health, social, economic, and environmental problems. Thus, in planning for prevention services, other state and local government agencies (substance abuse, mental health, education, and corrections), nongovernmental agencies, community representatives, and academic institutions must play a key role in identifying unmet needs. Representatives of communities at risk for HIV infection can provide invaluable personal and population-specific perspectives on accessibility and cultural appropriateness of specific prevention interventions.

Although different approaches to community planning may be taken in various communities, grantees will be required to address the following principles in all HIV Prevention Community Planning efforts supported by HIV Prevention Cooperative Agreement funds from CDC in FY 1995 and beyond:

1. HIV Prevention Community Planning represents an ongoing process involving the steps delineated in Section B.
2. HIV Prevention Community Planning reflects an open, candid, and participatory process, in which differences in background, perspective, and experience are essential and valued.
3. HIV Prevention Community Planning is characterized by shared priority-setting between organizations administering and awarding HIV prevention funds and the communities for whom the prevention services are intended.
4. Each grantee is required to identify at least one HIV Prevention Community Planning group (consideration should be given to the use of planning bodies/processes already in place) which reflects in its composition the characteristics of the current and projected epidemic in that jurisdiction (as evidenced in reported AIDS cases; HIV data, if available; and/or relevant surrogate markers). Other members of the planning group(s) should include scientific experts, service providers, and organizational representatives as delineated in Section E.
5. Nominations for membership are identified through an open process and candidates are selected based on criteria delineated in the application request for HIV community planning funds. In addition, the recruitment process for membership in the HIV Prevention Community Planning process is proactive to ensure that socioeconomically marginalized groups, and groups that are underserved by existing HIV prevention programs, are represented.
6. From the outset, all members of the HIV Prevention Community Planning group(s) understand the roles and responsibilities as outlined in this guidance

and agree to the procedures and ground rules used in all deliberations and decision making.

7. The starting point for defining future HIV prevention needs begins with an accurate epidemiologic profile of the present and future extent, distribution, and impact of HIV/AIDS in defined, targeted populations within the grantee's jurisdiction. In defining at-risk populations, special attention should be paid to distinguishing the behavioral, demographic, and racial/ethnic characteristics.
8. Identification, interpretation, and prioritization of HIV prevention needs reflect culturally relevant and linguistically appropriate information obtained from the communities to be served, particularly persons at risk for HIV infection and persons with HIV disease.
9. Assessment of HIV prevention needs is based on a variety of sources (both qualitative and quantitative), is collected using different assessment strategies (e.g., surveillance; survey; formative, process, and outcome evaluation of programs and services; outreach and focus group(s); public meetings), and incorporates information from both providers and consumers of services. Techniques such as oversampling may be needed to collect valid information from certain at-risk populations.
10. Priority setting for specific HIV prevention strategies and interventions is based on the following criteria:
  - (a) documented HIV prevention needs based on the current and projected impact of HIV/AIDS in defined populations in the grantee's jurisdiction;
  - (b) outcome effectiveness of proposed strategies and interventions (either demonstrated or probable);
  - (c) cost effectiveness of proposed strategies and interventions (either demonstrated or probable);
  - (d) sound scientific theory (e.g., behavior change, social change, and social marketing theories);
  - (e) values, norms, and consumer preferences of the communities for whom the services are intended;
  - (f) availability of other governmental and nongovernmental resources (including the private sector for HIV prevention); and
  - (g) other state and local determining factors. Each criterion should be formally considered by the HIV Prevention Community Planning group(s) during priority-setting deliberations.
11. Resources are provided to support all steps in the community planning process as listed in Section B, including facilitating the involvement of all participants in the planning process, particularly those persons at risk for HIV infection and persons with HIV disease.
12. Specific policies and procedures for resolving disputes and avoiding conflict of interest identified by the grantee or the planning group(s) are consistent with the



principles of this guidance, and are developed with input from all parties. These policies and procedures address conflict(s) of interest for members of the planning group(s) as well as disputes within and among planning group(s), differences between the planning group(s) and the grantee in the prioritization and implementation of programs/services, and a process for resolving these disputes in a timely manner when they occur.

13. The HIV Prevention Community Planning process includes the following evaluation components throughout the course of the project period: (a) developing goals and measurable objectives for the planning process; (b) monitoring the objectives; (c) evaluating the operation of the process; (d) evaluating the impact of the planning process; and (e) assessing the cost of the process.

These principles trace their origins to: ongoing HIV prevention program assessments conducted by CDC staff; CDC's Planned Approach to Community Health (PATCH) program; CDC's Assessment Protocol for Excellence in Public Health (APEX/PH) project; the ASTHO/NASTAD/CSTE State Health Agency Vision for HIV Prevention; findings of CDC's 1993 HIV external review process; experience and recommendations of health departments and nongovernmental organizations; and the health promotion, community development, and behavioral/social sciences literature.

## E. LOGISTICS OF HIV PREVENTION COMMUNITY PLANNING

Beginning in FY 1994, applicants for cooperative agreement funds under program announcement #300 will be required to adhere to the principles of HIV Prevention Community Planning outlined in this document. Each recipient of cooperative agreement funds under this announcement will be required to base its funding application for FY 1995 on the results of an HIV Prevention Community Planning process that will be implemented in FY 1994. Grantees are expected to base subsequent applications on this ongoing community planning process.

In FY 1994, supplemental funds are being provided through this program announcement to specifically support HIV Prevention Community Planning. These funds should be used to (a) support planning group meetings, public meetings, and other means for obtaining community input; (b) support capacity development for parity, inclusion, and representation of community representatives and for other members of planning groups to participate effectively in the process; (c) provide technical assistance to health departments and community planning groups by outside experts; (d) support planning infrastructure for the HIV community planning process; and (e) collect and/or analyze and disseminate relevant data. The distribution of planning funds within these five categories should be determined jointly by the HIV Prevention Community Planning Group and the grantee (also see Section H).

All grantees directly receiving funds under cooperative agreement #300 will be required to conduct HIV Prevention Community Planning in FY 1994. Grantees will be required to determine how best to achieve and integrate statewide, regional, and community planning within their jurisdictions. Grantees must collaborate with governmental and nongovernmental organizations and affected communities to determine the most effective mechanisms for input into the HIV Prevention Community Planning process. Identification of these mechanisms should be based on a dialogue between the state and local public health agencies and the community. The process must be structured in such a way that it incorporates and addresses needs and priorities identified at the community level (i.e., the level closest to where the problem is identified). Models for obtaining input *include but are not limited to* a state-wide planning model, a regional planning model, a Metropolitan Statistical Area planning model, and/or existing planning bodies.

Grantees will be responsible for developing criteria for selecting the individual members of the HIV Prevention Community Planning group(s) within their jurisdiction. State grantees should involve local public health authorities and leaders of affected communities in developing such criteria; local grantees should similarly involve state health authorities and leaders of affected communities in developing such methods. Special emphasis should be placed on procedures for identifying representatives of socioeconomically marginalized groups and groups that are underserved by existing HIV prevention programs.

The HIV Prevention Community Planning process must include representatives who reflect the population characteristics of the current and projected HIV/AIDS epidemic in that jurisdiction as indicated by reported AIDS cases, HIV data, if available; and other relevant surrogate markers, in terms of age, gender, race/ethnicity, socioeconomic status, geographic distribution (e.g., special needs of small MSA or rural populations), sexual orientation, and HIV exposure category. In addition to reflecting the population characteristics outlined above, it is important that these representatives articulate for and have expertise in understanding and addressing the specific HIV prevention needs of the populations they represent. Representation should also include (a) state and local health departments, state and local education agencies and other relevant governmental agencies (substance abuse, mental health, corrections); (b) experts in epidemiology, behavioral and social sciences, evaluation research, and health planning; and (c) representatives of a sample of nongovernmental and governmental organizations providing HIV prevention and related services (e.g., STD, TB, substance abuse prevention and treatment, mental health services, HIV care and social services, etc.) to persons at risk for HIV infection or already infected. The HIV Prevention Community Planning process should attempt to accommodate a reasonable number of representatives without becoming so large that it cannot effectively function. HIV Prevention Community Planning group(s) are encouraged to seek additional avenues for obtaining input on community HIV prevention needs and priorities, such as holding well-publicized public meetings, conducting focus groups, and convening ad hoc panels.

HIV Prevention Community Planning group(s) should have access to current information related to HIV prevention from evaluation of programs and the behavioral and social sciences, especially as it relates to the at-risk population groups within a given community. Planning group members should also be routinely updated about relevant new findings of behavioral and social scientists.

Every CDC grantee receiving funding under program announcement #300 is responsible for identifying a health department employee, or a designated representative, to co-chair each HIV planning group in the project area; if state grantees implement more than one planning group within their jurisdiction, they may wish to designate local health department representatives as co-chairs of these planning groups. The group, once convened, selects the other co-chair.

The HIV Prevention Community Planning Group(s) should be routinely informed by the grantee of other relevant planning efforts, particularly the process for allocating Titles I, II, and IIIb of the Ryan White Comprehensive AIDS Resources Emergency Act. Grantees should consider merging the HIV Prevention Community Planning process with other planning bodies/processes already in place. *If such mergers are undertaken, grantees must adhere to the Principles of HIV Prevention Community Planning, as specified in Section D.*

The HIV Prevention Community Planning process should result in a Comprehensive HIV Prevention Plan, jointly developed by the grantee and the HIV Prevention Community Planning group(s), which includes specific, high-priority HIV prevention strategies and interventions targeted to defined populations to be supported with HIV prevention cooperative agreement funds. Thus, each grantee's application for FY 1995 funds (and beyond) should address the plan's high priority elements in its application for funds under program announcement #300. In those jurisdictions where CDC has direct cooperative agreements with both state and local health departments, grantees are expected to coordinate planning with one another prior to finalizing their own HIV prevention applications.

Each grantee, in its FY 1995 application and beyond, must include a letter of concurrence or nonconcurrence from each HIV Prevention Community Planning group convened within the grantee's jurisdiction. Letters of concurrence would indicate the extent to which the grantee and the HIV Prevention Community Planning group(s) have successfully collaborated in developing a comprehensive HIV prevention community plan and agree upon the program priorities contained in the application. An HIV Community Planning group that disagrees with the program priorities identified in the grantee's application should cite specific reasons for nonconcurrence. In those instances where a grantee does not concur with the findings or recommendations of the HIV Prevention Community Planning group(s) and believes the public health would be better served by funding HIV prevention activities/services that are substantially different, it must submit a

letter of justification in its application. CDC will evaluate and assess these justifications on a case-by-case basis to make final determinations for award of funds.

Grantees are responsible for operationalizing and implementing HIV prevention services/activities outlined in the comprehensive plan, including selecting the specific organizations/entities that should provide HIV prevention services/activities, and awarding and administering HIV prevention funds.

Some grantees may be unable to complete all aspects of the HIV Prevention Community Planning process in FY 1994. At a minimum, all grantees will be expected to (a) identify and convene an HIV Prevention Community Planning group(s); (b) determine the present and future extent, distribution, and impact of HIV/AIDS in defined populations within the grantee's jurisdiction; (c) conduct an HIV prevention needs assessment; and (d) begin the prioritization process. If the grantee and the community planning group(s) are unable to finalize the comprehensive HIV prevention plan before the grantee is required to complete and submit the application for FY 1995 funding, the grantee, *with the written concurrence of the community planning group(s) in that jurisdiction*, may request an extension of time to complete the planning process. CDC will evaluate and assess these requests on a case-by-case basis to make a final determination.

If CDC determines that additional time is necessary to complete the planning process, the extension will be granted contingent on the understanding that the grantee will still be required to submit an initial FY 1995 application to the HIV Prevention Community Planning group(s) in that jurisdiction for review and written comment on the program priorities identified in the grantee's application. This review and comment should be based on the objective information obtained from the HIV prevention needs assessment and the analysis of the extent, distribution, and impact of HIV/AIDS in defined populations within the grantee's jurisdiction. Upon completion of the comprehensive HIV prevention plan, the grantee will submit a revised FY 1995 application to CDC.

#### F. RESTRICTIONS

Funds for the HIV Prevention Community Planning process will be awarded through the HIV Prevention Cooperative Agreements with state, territorial, and local health departments on or about January 15, 1994. However, planning funds will be restricted in the following manner: (a) up to one-half of the planning funds will be released upon receipt of a written assurance that the grantee will comply with the Principles (Section D) and Logistics (Section E) delineated in this guidance, and (b) the remaining funds will be released upon approval of the application described in Section G.

Upon receipt of the planning application, CDC will review each grantee's planning application for compliance with the principles and logistics outlined in this guidance.

When approved, restrictions on the expenditure of remaining planning funds will be removed.

## G. PLANNING APPLICATION CONTENT

Applications for awards of planning funds under CDC program announcement #300 must include (a) a detailed and itemized description of the proposed structure and timetable for the HIV Prevention Community Planning process throughout that jurisdiction (e.g., number, location, jurisdiction, and size of the planning group(s); proposed merger with existing planning bodies; designated health department co-chairs, and (b) criteria and procedures for nominating, recruiting, and selecting members of the HIV Prevention Community Planning group(s), including a description of specific collaboration with governmental and nongovernmental organizations and affected communities on this issue.

Recipients are encouraged to submit a plan as soon as possible, but are required to submit one no later than February 28, 1994.

## H. ROLES AND RESPONSIBILITIES

### GRANTEES

The role of grantees in the HIV Prevention Community Planning process is to:

1. Administer and coordinate public funds from a variety of sources, including Federal, state, and local agencies, to prevent HIV transmission and reduce associated morbidity and mortality.
2. Administer HIV prevention funds awarded under the cooperative agreement, ensuring that funds are awarded to contractors in a timely manner, monitoring contractor activities, and documenting contractor compliance.
3. Provide HIV/AIDS surveillance and other relevant data and analyses of statewide, regional, and/or local data to assist the HIV community planning process in establishing program priorities based on the current and future extent, distribution, and impact of the HIV/AIDS epidemic.
4. Collaborate with state, local, and community partners to determine the most effective means for implementing HIV Prevention Community Planning in their jurisdiction (see Section D).
5. Ensure that specific policies are in place articulating the roles and responsibilities of the various components of the HIV Prevention Community Planning process.

6. Establish policies that address planning group composition, selection, appointment, and terms of office, in consultation with health authorities and community leaders in that jurisdiction.
7. Ensure that all planning group(s) reflect the population characteristics of the current epidemic in state and local jurisdictions in terms of age, race/ethnicity, gender, sexual orientation, geographic distribution, and HIV exposure category.
8. Provide expertise and technical assistance, including ongoing training on HIV prevention planning and the interpretation of epidemiologic and evaluation data, to ensure that the planning process is comprehensive and scientifically valid.
9. Promote linkages among the local community HIV prevention services providers, public health agencies, and behavioral and social scientists who are either in the local area or who are familiar with local prevention needs, issues, and at-risk populations.
10. Develop an application for HIV prevention cooperative agreement funds based on the comprehensive HIV prevention plan(s) developed through the HIV Prevention Community Planning process.
11. Ensure that technical assistance is provided to meet the needs of grantees and community-based providers in the areas of program planning, intervention, and evaluation as identified in the HIV prevention plan. Grantees should meet these needs by drawing on expertise from a variety of sources (e.g., health departments, academia, professional and other national organizations, and nongovernmental organizations).
12. Allocate resources based on the Comprehensive HIV Prevention Plan.
13. Ensure program effectiveness through specific evaluation activities, including conducting or contracting for outcome evaluation studies, providing technical assistance in evaluation, or ensuring the provision of evaluation technical assistance to funding recipients.

#### HIV PREVENTION COMMUNITY PLANNING GROUP(S)

The role of the planning group(s) in the HIV Prevention Community Planning process is to:

1. Delineate technical assistance/capacity development needs for effective community participation in the planning process.



2. Review available epidemiologic, evaluation, behavioral and social science, cost-effectiveness, and needs assessment data and other information required to prioritize HIV prevention needs, and collaborate with the health department on how best to obtain additional data and information.
3. Assess existing community resources to determine the community's capability to respond to the HIV epidemic.
4. Identify unmet HIV prevention needs within defined populations.
5. Prioritize HIV prevention needs by target populations and propose high priority strategies and interventions.
6. Identify the technical assistance needs of community-based providers in the areas of program planning, intervention, and evaluation.
7. Consider how CTRPN; early intervention, primary care, and other HIV-related services; STD, TB, and substance abuse prevention and treatment; mental health services; and other public health needs are addressed within the Comprehensive HIV Prevention Plan.
8. Evaluate the HIV Prevention Community Planning process and assess the responsiveness and effectiveness of the grantee's application in addressing the priorities identified in the comprehensive HIV prevention plan.

#### SHARED RESPONSIBILITY BETWEEN GRANTEEES AND HIV PREVENTION COMMUNITY PLANNING GROUP(S)

1. Select co-chairs for HIV Prevention Community Planning Group(s): Grantees select a health department employee, or a designated representative as one co-chair, and the community planning group selects the other.
2. Develop procedures that address (a) policies and provisions for reaching decisions and policies on attendance at meetings; (b) resolution of disputes identified in planning deliberations; and (c) resolution of conflict(s) of interest for members of the planning group(s).
3. Determine the distribution of planning funds to (a) support planning group meetings, and the participation of group members, public meetings, and other means for obtaining community input; (b) support capacity development for parity, inclusion, and representation of community representatives, and for other members of the planning groups to participate effectively in the process; (c) provide technical assistance by outside experts to health departments and community planning groups; (d) support community health planning infrastructure

for the HIV community planning process; and (e) collect and/or analyze and disseminate relevant data.

4. Assess the present and future extent, distribution, and impact of HIV/AIDS in defined populations in the jurisdiction in which the planning is taking place.
5. Conduct a needs assessment process to identify unmet HIV prevention needs within defined populations.
6. Identify specific high priority strategies and interventions for defined target populations.
7. Develop goals and measurable objectives for HIV prevention strategies and interventions in defined target populations.
8. Integrate multiple HIV community prevention plans into a project-wide Comprehensive HIV Prevention Plan and foster integration of the HIV Prevention Community Planning process with other relevant planning efforts.
9. Develop and periodically update a comprehensive HIV prevention plan including the provision of technical assistance to meet the needs of grantees and community-based providers in the areas of program planning, implementation, and evaluation.

#### CENTERS FOR DISEASE CONTROL AND PREVENTION

The role of CDC in the HIV Prevention Community Planning process is to:

1. Collaborate with health departments, national organizations, federal agencies, and academic institutions to ensure the provision of technical/program assistance and training for the HIV Prevention Community Planning process. Technical/program assistance will help recipients to understand how to (a) ensure parity, inclusion, and representation of all members throughout the community planning process; (b) analyze epidemiologic, behavioral and other relevant data to assess the impact and extent of the HIV/AIDS epidemic in defined populations; (c) conduct needs assessments and prioritize unmet HIV prevention needs; (d) identify and evaluate effective and cost-effective HIV prevention activities for these priority populations; (e) provide access to needed behavioral and social science expertise; and (f) identify and manage dispute and conflict of interest issues.
2. Require that application content submitted by HIV Prevention Cooperative Agreement recipients for HIV Prevention Community Planning funds is in accordance with the principles in this guidance.



3. Monitor the HIV Prevention Community Planning process.
4. Require as a condition for award of cooperative agreement funds that recipients' FY 1995 applications are in accordance with the comprehensive plan developed as a result of the HIV Prevention Community Planning process or include an acceptable letter of justification as delineated in Section D.
5. Identify the minimal program components of a comprehensive HIV prevention program.
6. Collaborate with grantees in evaluating HIV prevention programs.
7. Collaborate with other federal agencies (particularly the National Institutes of Health, the Substance Abuse and Mental Health Services Administration, and the Health Resources and Services Administration) in promoting the transfer of new information and emerging prevention technologies or approaches (i.e., epidemiologic, biomedical, operational, behavioral, or evaluative) to health departments and other prevention partners, including nongovernmental organizations.
8. Compile annually a report on the projected expenditures of HIV prevention cooperative agreement funds by specific strategies and interventions. Collaborate with other prevention partners in improving and integrating fiscal tracking systems.

In addition to supplemental funds awarded for HIV Prevention Community Planning in FY 1994, state and local health departments will receive an increase in new funds awarded for HIV prevention over those awarded in FY 1993. Grantees are encouraged to delay the long-term commitment of part or all of these additional HIV prevention funds to implement unmet program needs, as identified by HIV Prevention Community Planning group(s), during FY 1994.

#### APPLICATION SUBMISSION AND DEADLINE

The original and two copies of the application (PHS Form 5161-1) must be submitted to Elizabeth M. Taylor, Grants Management Officer, Procurement and Grants Office, Centers for Disease Control and Prevention, 255 East Paces Ferry Road, N.E., Mailstop E16, Atlanta, GA 30305 on or before *February 28, 1994*.

#### WHERE TO OBTAIN ADDITIONAL INFORMATION

Business management technical assistance including information on application procedures and copies of application forms may be obtained from Marsha Driggans,

Grants Management Specialist, Grants Management Branch, Procurement and Grants Office, Centers for Disease Control and Prevention, 255 East Paces Ferry Road, N.E., Mailstop E16, Atlanta, GA 30305, (404) 842-6523.

HIV Prevention, Community Planning Supplement must be referenced in all requests for information pertaining to this project.

Programmatic technical assistance may be obtained from your CDC project officer Division of Sexually Transmitted Diseases/HIV Prevention, Center for Prevention Services, Centers for Disease Control and Prevention, Mailstop E44, Atlanta, GA 30333, (404) 639-8315.

## Appendices



Appendix A  
Behavioral Science Theory

## Appendix A

### Environmental Science Project

# Appendix A

## Behavioral Science Theory

### INTRODUCTION

A general understanding of the behavioral and social science theory underlying the development of behaviorally-based prevention interventions is important to grantees and community planning groups for several reasons. First, many of the articles in the literature on intervention effectiveness include a description of the theory used to design the prevention intervention. In order to understand this literature, planners must be familiar with common theories. Second, while planning a comprehensive HIV prevention program, there may be unmet needs for which there are no proven interventions (e.g., for a particular population) reported in the literature. Therefore, planning groups will need to make recommendations about the types of interventions that may address these unmet needs. A basic foundation in behavior theory will be essential to planning groups who are faced with this task. As pointed out in Chapter 6, the extent to which an intervention is theory-based is one of the attributes community planning groups should use in prioritizing interventions. This appendix presents a brief description of some of the major theories from the behavioral and social science literature that have been used in HIV/AIDS prevention research.

### THEORIES OF BEHAVIOR—A PRIMER

To develop and choose among interventions to change human behavior, it is useful to understand why people behave the way they do. Stated another way, the more we know about the factors underlying the performance or nonperformance of a behavior, the more successful we can be at designing an intervention that successfully influences that

behavior. Research can be done to determine which of several theoretical factors predicts or explains a particular behavior in a particular population. Interventions can then be developed to influence these intervening factors and thus to facilitate the desired prevention behavior.

There are many different theories of human behavior and behavior change that have been used to understand, explain, and predict health behavior. Of these many theories of behavior, three have been most frequently used in the behavioral and social science research on the prevention of HIV infection: the Health Belief Model, the Theory of Reasoned Action, and Social Cognitive Learning Theory. In addition to these three major theoretical models, there is a Transtheoretical Model that focuses on Stages of Behavior Change. Good reviews of the specific dimensions of each theory are found in Leviton (1989; 1990) and Baranowski (1990). The following discussion presents basic principles for each of these theories, provides references for further more detailed reading and illustrates how the relevant factors might underly HIV prevention interventions.

### HEALTH BELIEF MODEL

The Health Belief Model is essentially a health education approach to behavior and intervention design. The model has been used to explain and understand a wide variety of health behaviors, including prevention and screening behaviors like participation in cardiovascular screening, immunization and checkup programs as well as treatment behavior like smoking cessation and compliance with dialysis regimens (Janz and Becker, 1984; Kirscht and Joseph, 1989; Rosenstock, 1974). More recently, it has been applied to behaviors that place people at risk of

Note: This manuscript is authored by Richard Windsor, PhD, Susan E. Middlestadt, PhD, and David Holtgrave, PhD.

HIV infection (e.g., Becker, 1988; Kirscht and Joseph, 1989; Montgomery et al., 1989).

As the name implies, the Health Belief Model assumes that health behavior is a function of four key health beliefs: the perceived personal susceptibility or vulnerability to the negative health condition; the perceived severity of the condition; the perceived efficacy of the behavior in dealing with the condition; and, the barriers to the behavior. Together, these belief components produce a readiness to act. In addition, many proponents of the health belief model recognize that cues to action are necessary to initiate action once the readiness is above threshold and that a variety of personal and social characteristics such as age, sex, knowledge, and culture play a role in modifying the behavior if and when it occurs.

An HIV-prevention intervention designed, for example, to facilitate correct and consistent condom use based on the health belief model would try to influence these theoretical factors. The intervention might try to get individuals to realize that their behaviors place them at risk of HIV infection, thus increasing their perception that they are susceptible or vulnerable to HIV infection. Alternatively, it might focus on the severity factor, a person's belief that AIDS is a deadly disease, or the effectiveness factor, the belief that correct and consistent condom use will effectively prevent or reduce HIV infection. An intervention that encouraged people to carry condoms would be addressing a possible barrier to condom use. Messages in the mass media that reminded people to use condoms could be construed as providing cues to action. Ideally, the choice of the factor to address with an intervention would be made on the basis of behavioral research that identified that factor as an important determinant in the particular population of interest.

## THEORY OF REASONED ACTION

The Theory of Reasoned Action, a social psychological approach to behavior, assumes that changing behavior is a matter of changing the cognitive structure underlying the behavior in question. The theory is a general theory of behavior that deals with the relations among beliefs, attitudes, intentions, and behavior (Ajzen and Fishbein, 1980; Fishbein and Ajzen, 1975) and has been used to understand behaviors from a variety of domains including health in general and HIV/AIDS in particular (Fishbein and Middlestadt, 1989; Fishbein et al., 1991).

In some respects, the theory is best seen as a series of four hypotheses. At the first level, a behavior is assumed to be primarily a function of a person's intention to perform that behavior. At the next level, the intention to perform the behavior is seen as a function of the weighted combination of two factors, a personal factor (the attitude toward the behavior) and a social factor (subjective norm). The attitude toward the behavior is the feeling of favorableness toward the behavior; the subjective norm is the perception that important others think that he or she should (or should not) perform the behavior. Underlying the attitude toward the behavior is an underlying cognitive structure of behavioral beliefs that performing the behavior will lead to certain outcomes and the evaluation of these outcomes. Underlying the subjective norm is an underlying cognitive structure of normative beliefs that particular individuals or groups think that one should or should not perform the behavior and the person's motivation to comply with each of these significant others.

An intervention to encourage correct and consistent condom use that is based on the Theory of Reasoned Action would address either the cognitive structure underlying the attitude toward the behavior or the subjective norm. For example, an intervention that convinced people that correct and consistent condom use effectively reduced risk of other sexually transmitted diseases would be addressing the behavioral belief factor underlying the attitude toward the behavior, facilitating a more favorable attitude, making the intention more positive and thus increasing the likelihood that the behavior will be performed. Note that, according to the Theory of Reasoned Action, beliefs about outcomes other than health outcomes might be important determinants. Thus, to deal with the behavioral belief that condom use might have led to distrust in the relationship, an intervention might need to be developed to facilitate ways to introduce condoms among partners that strengthened rather than threatened the relationship. From a normative perspective, an intervention that reinforced the normative belief that peers expected the person to use condoms correctly and consistently would be addressing the cognitive structure underlying the subjective norm, making the person perceive more normative pressure, have a more positive intention, and thus be more likely to use a condom correctly and consistently. Again, ideally the choice of the particular factor to address would be based on empirical research in the target population of interest.



## SOCIAL COGNITIVE LEARNING THEORY

The roots of Social Cognitive Learning Theory lie in the learning approaches to psychology as well as in clinical psychology applications to correct dysfunctional behaviors. Learning theory focuses on behavior and the antecedents and consequences of behavior in the environment. By contrast, Social Cognitive Learning Theory recognizes the important role of cognitive interpretations. That is, Social Cognitive Learning Theory (Bandura, 1977; 1986) is based on a triadic relationship among the person, behavior, and the environment through a process called "reciprocal determinism." In other words, whereas the environment largely determines or causes behavior, the person uses cognitive processes to interpret both the environment and his or her behavior, and also behaves in ways to change the environment and meet with more favorable behavior outcomes. This theory has been used effectively to explain and change a diverse set of health behaviors such as smoking cessation, weight reduction, increase in exercise and contraceptive practices, and recently AIDS prevention (Bandura, 1989; 1991).

According to Social Cognitive Learning Theory, two sets of cognitions are important in understanding and changing behavior: outcome expectations and self-efficacy. Outcome expectations include a person's interpretations of the consequences of performing the behavior. The person will perform the behavior to the extent that he/she believes it will pay off or will lead to positive consequences and avoid negative consequences. This aspect of Social Cognitive Learning Theory is very similar to the Theory of Reasoned Action. Self-efficacy is the person's belief in their capabilities and confidence in performing the behavior, their belief that they can choose to do it under difficult circumstances, and can persevere in the face of difficulties.

These self-efficacy cognitions represent a particularly important contribution of Social Cognitive Learning Theory. Just considering the HIV-prevention behavior of correct and consistent condom use, it is clear that skills at buying, correctly using, having available, and discussing and overcoming partner's resistance are vital. And, people must not only have these skills but must be confident in their abilities, they must have self-efficacy. Theoretically, a person with a strong sense of self-efficacy would be more likely to try a behavior, set a higher goal for how well or often the behavior is performed, persevere longer, use a variety of strategies, and try again when faced

with temporary setbacks.

An intervention based on Social Cognitive Learning Theory might have people watch models successfully negotiating condom use with a partner in a variety of different circumstances. These materials could not only teach negotiation skills but could promote self-efficacy or confidence in abilities as well as demonstrate possible positive outcomes of effective negotiation.

## COMMON FACTORS UNDERLYING THE THREE BEHAVIORAL THEORIES

Fortunately for the program planner attempting to set priorities among interventions based on sound behavioral and social scientific theory, there is a significant amount of overlap and consistency among these three major theories of behavior. In fact, based on a series of meetings among theorists representing each of these theories, a list of eight basic or common factors has been identified (Fishbein et al., 1993). These factors not only represent points of consensus among the theorists, but have been empirically shown to account for or explain most of the variation in any given behavior. These eight factors were summarized in a National Commission on AIDS 1993 report (National Commission on AIDS, 1993) and are shown in Table A-1.

## TRANSTHEORETICAL MODEL

As implied by its name, the Transtheoretical (or Stages of Change) Model attempts to explain health behavior independent of specific theoretical factors. Instead, this model (Prochaska and DiClemente, 1986) proposes that behavior change occurs in a series of stages. This model assumes that individuals start with no intention to change, form weak intentions, strengthen these intentions, try the behavior inconsistently at first, and then finally adopt the new behavior as a routine part of their lives. These stages are described in Table A-2.

Movement through the stages will vary greatly from population to population and from individual to individual. Some people may remain in the contemplative stage for months or years; others cycle back and forth between stages. Once a person initiates or adopts a behavior, that person is vulnerable to relapse. Effective interventions first determine where the population is on this continuum of behavior change and move them to the subsequent, more advanced stage. Baseline and follow-up assessments of the percentage

of population of interest will help the planning group to plan interventions and assess progress and movement through the stages.

Public health interventions have often been developed for populations in the preparation stage by promoting an immediate behavior change, like consistent condom use. However, according to this theory, when the majority of the target population is in the pre-contemplation stage, this type of intervention will only be partly effective in promoting behavior change. To be effective, intervention methods and messages must be targeted to the specific needs and stage of a group. The various factors from the three major theories, the Health Belief Model, the Theory of Reasoned Action, and Social Cognitive Learning Theory, can help move persons from stage to stage in the Transtheoretical Model. For example, to motivate individuals at the pre-contemplation stage to form intentions, an intervention might first alert them of the potential danger of not changing by creating a perception of risk. For individuals at the preparation stage who have formed an intention to behavior, an intervention might try to increase the self-efficacy for the behavior. For further information on how this might be done, see Baranowski (1990) and O'Reilly and Higgins (1991).

## THE IMPORTANCE OF SOUND SCIENTIFIC THEORY FOR DESIGNING, EVALUATING, AND SELECTING AMONG HIV PREVENTION INTERVENTIONS

There are a number of advantages to understanding and using sound behavior and social science theory. Research to identify the factors associated with the behaviors that place people at increased risk of infection and thus to identify behavioral determinants to be addressed by intervention is more effective and interpretable if it is guided by sound theory. The theories serve to outline important behavioral factors, to indicate ways of measuring these factors and to facilitate the communication of the results. Put most simply, evaluation research that identifies not only that behavior changed but which intervening factor contributed to that change allows the planner to understand why the intervention worked, thus increasing the likelihood of successfully replicating it.

No one theoretical model has been found to predict human behavior with complete success. However, even imperfect theories can provide useful guidance in designing, evaluating and choosing among HIV prevention interventions. Important opportunities to translate the components of behavioral theories into public health practice remain. For further information on this topic, see Valdiserri et al. (1992).

**Table A-1: Common Theoretical Factors**

The Population at Risk Must:	Factor
1. Believe the advantages of performing the behavior (benefits) exceed the disadvantages	Expected Outcomes (attitude)
2. Have formed a strong positive intention or be committed to perform a behavior	Intention
3. Possess the skills to perform a behavior	Skills
4. Believe that they can perform a behavior	Self-Efficacy
5. Believe that the performance of a behavior will more likely produce a positive than a negative emotional response	Emotion
6. Believe that the performance of a behavior is consistent with their self-image	Self-Standards
7. Perceive greater social pressure to perform a behavior than not to perform it	Perceived social norms
8. Experience fewer environmental constraints to perform a behavior than not to perform it	Barriers

Adapted from National Commission on AIDS, 1993

**Table A-2: Stages in the Transtheoretical Model**

	Stage Description
1. Pre-contemplation	People in this stage have no intention to change behavior in the foreseeable future, are unaware of the risk, or deny the consequences of risk behavior.
2. Contemplation	People are aware that a problem exists, are seriously thinking about overcoming it, but have not yet made a commitment to take action.
3. Preparation	People intend to take action in the near future and may have taken some inconsistent action in the recent past.
4. Action	People modify their behavior, experiences, or environment to overcome their problems; the behavior change is relatively recent.
5. Maintenance	People work to prevent relapse and maintain the behavior change over a "long" period of time.

Adapted from Prochaska and DiClemente, 1986

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